
JMIR Public Health and Surveillance

Impact Factor (2023): 3.5
Volume 6 (2020), Issue 4 ISSN 2369-2960 Editor in Chief: Travis Sanchez, PhD, MPH

Contents

Editorial

- Population Size Estimation Methods: Searching for the Holy Grail ([e25076](#))
Joyce Neal, Dimitri Prybylski, Travis Sanchez, Wolfgang Hladik. 6

Original Papers

- Availability and Quality of Surveillance and Survey Data on HIV Prevalence Among Sex Workers, Men Who Have Sex With Men, People Who Inject Drugs, and Transgender Women in Low- and Middle-Income Countries: Review of Available Data (2001-2017) ([e21688](#))
Sonia Arias Garcia, Jia Chen, Jesus Calleja, Keith Sabin, Chinelo Ogbuanu, David Lowrance, Jinkou Zhao. 13
- YouTube Video Comments on Healthy Eating: Descriptive and Predictive Analysis ([e19618](#))
Shasha Teng, Kok Khong, Saeed Pahlevan Sharif, Amr Ahmed. 25
- Geographic Differences in Cannabis Conversations on Twitter: Infodemiology Study ([e18540](#))
Jenna van Draanen, HaoDong Tao, Saksham Gupta, Sam Liu. 38
- E-Cigarette Promotion on Twitter in Australia: Content Analysis of Tweets ([e15577](#))
Kahlia McCausland, Bruce Maycock, Tama Leaver, Katharina Wolf, Becky Freeman, Katie Thomson, Jonine Jancey. 48
- Nowcasting Sexually Transmitted Infections in Chicago: Predictive Modeling and Evaluation Study Using Google Trends ([e20588](#))
Amy Johnson, Runa Bhaumik, Irina Tabidze, Supriya Mehta. 68
- How Internet Contracts Impact Research: Content Analysis of Terms of Service on Consumer Product Websites ([e23579](#))
Caitlin Weiger, Katherine Smith, Joanna Cohen, Mark Dredze, Meghan Moran. 97
- E-Cigarette Advocates on Twitter: Content Analysis of Vaping-Related Tweets ([e17543](#))
Kahlia McCausland, Bruce Maycock, Tama Leaver, Katharina Wolf, Becky Freeman, Jonine Jancey. 113
- Electronic Cigarette–Related Contents on Instagram: Observational Study and Exploratory Analysis ([e21963](#))
Yankun Gao, Zidian Xie, Li Sun, Chenliang Xu, Dongmei Li. 126
- Public Response to a Social Media Tobacco Prevention Campaign: Content Analysis ([e20649](#))
Anuja Majmundar, NamQuyen Le, Meghan Moran, Jennifer Unger, Katja Reuter. 137

Peer Recruitment Strategies for Female Sex Workers Not Engaged in HIV Prevention and Treatment Services in Côte d'Ivoire: Program Data Analysis (e18000)
 Oluwasolape Olawore, Hibist Astatke, Tiffany Lillie, Navindra Persaud, Carrie Lyons, Didier Kamali, Rose Wilcher, Stefan Baral. 146

Understanding the Extent of Adolescents' Willingness to Engage With Food and Beverage Companies' Instagram Accounts: Experimental Survey Study (e20336)
 Samina Lutfeali, Tisheya Ward, Tenay Greene, Josh Arshonsky, Azizi Seixas, Madeline Dalton, Marie Bragg. 158

Independent and Combined Associations of Physical Activity, Sedentary Time, and Activity Intensities With Perceived Stress Among University Students: Internet-Based Cross-Sectional Study (e20119)
 Shu Tan, Malte Jetzke, Vera Vergeld, Carsten Müller. 168

Outcomes of the Deployment of the Auto-Visual Acute Flaccid Paralysis Detection and Reporting (AVADAR) System for Strengthening Polio Surveillance in Africa From 2017 to 2018: Evaluation Study (e18950)
 Johnson Ticha, Godwin Akpan, Lara Paige, Kamel Senouci, Andrew Stein, Patrick Briand, Jude Tuma, Daniel Oyaole, Reuben Ngofa, Sylvester Maleghemi, Kebba Touray, Abdullahi Salihu, Mamadou Diallo, Sisay Tegegne, Isah Bello, Umar Idris, Omosivie Maduka, Casimir Manengu, Faisal Shuaib, Michael Galway, Pascal Mkanda. 192

Barriers to Creating Scalable Business Models for Digital Health Innovation in Public Systems: Qualitative Case Study (e20579)
 Leah Kelley, Jamie Fujjoka, Kyle Liang, Madeline Cooper, Trevor Jamieson, Laura Desveaux. 202

An Interactive Text Message Survey as a Novel Assessment for Bedtime Routines in Public Health Research: Observational Study (e15524)
 George Kitsaras, Michaela Goodwin, Julia Allan, Michael Kelly, Iain Pretty. 215

Antivaccine Messages on Facebook: Preliminary Audit (e18878)
 Dhamanpreet Dhaliwal, Cynthia Mannion. 224

Trends and Predictors of COVID-19 Information Sources and Their Relationship With Knowledge and Beliefs Related to the Pandemic: Nationwide Cross-Sectional Study (e21071)
 Shahmir Ali, Joshua Foreman, Yesim Tozan, Ariadna Capasso, Abbey Jones, Ralph DiClemente. 239

Novel Approach to Support Rapid Data Collection, Management, and Visualization During the COVID-19 Outbreak Response in the World Health Organization African Region: Development of a Data Summarization and Visualization Tool (e20355)
 Kamran Ahmed, Muhammad Bukhari, Tamayi Mlanda, Jean Kimenyi, Polly Wallace, Charles Okot Lukoya, Esther Hamblion, Benido Impouma. 2

Transmission Dynamics of the COVID-19 Epidemic at the District Level in India: Prospective Observational Study (e22678)
 Suman Saurabh, Mahendra Verma, Vaishali Gautam, Nitesh Kumar, Akhil Goel, Manoj Gupta, Pankaj Bhardwaj, Sanjeev Misra. 264

The Resurgence of Cyber Racism During the COVID-19 Pandemic and its Aftereffects: Analysis of Sentiments and Emotions in Tweets (e19833)
 Akash Dubey. 274

Deployment of a Smart Handwashing Station in a School Setting During the COVID-19 Pandemic: Field Study (e22305)
 Jeremy Herbert, Caitlin Horsham, Helen Ford, Alexander Wall, Elke Hacker. 281

Diagnostic Accuracy of Chest Computed Tomography Scans for Suspected Patients With COVID-19: Receiver Operating Characteristic Curve Analysis (e19424)
 Lianpin Wu, Qike Jin, Jie Chen, Jiawei He, David Brett-Major, Jianghu Dong. 292

Social Media as an Early Proxy for Social Distancing Indicated by the COVID-19 Reproduction Number: Observational Study (e21340)	
Joseph Younis, Harvy Freitag, Jeremy Ruthberg, Jonathan Romanes, Craig Nielsen, Neil Mehta.	302
Online Public Attention During the Early Days of the COVID-19 Pandemic: Inveillance Study Based on Baidu Index (e23098)	
Xue Gong, Yangyang Han, Mengchi Hou, Rui Guo.	310
Concerns and Misconceptions About the Australian Government’s COVIDSafe App: Cross-Sectional Survey Study (e23081)	
Rae Thomas, Zoe Michaleff, Hannah Greenwood, Eman Abukmail, Paul Glasziou.	323
Public Perception of the COVID-19 Pandemic on Twitter: Sentiment Analysis and Topic Modeling Study (e21978)	
Sakun Boon-Itt, Yukolpat Skunkan.	330
Analysis of the COVID-19 Epidemic Transmission Network in Mainland China: K-Core Decomposition Study (e24291)	
Lei Qin, Yidan Wang, Qiang Sun, Xiaomei Zhang, Ben-Chang Shia, Chengcheng Liu.	347
Reinfection with SARS-CoV-2: Discrete SIR (Susceptible, Infected, Recovered) Modeling Using Empirical Infection Data (e21168)	
Andrew McMahon, Nicole Robb.	364
COVID-19 Surveillance in a Primary Care Sentinel Network: In-Pandemic Development of an Application Ontology (e21434)	
Simon de Lusignan, Harshana Liyanage, Dylan McGagh, Bhautesh Jani, Jorgen Bauwens, Rachel Byford, Dai Evans, Tom Fahey, Trisha Greenhalgh, Nicholas Jones, Frances Mair, Cecilia Okusi, Vaishnavi Parimalanathan, Jill Pell, Julian Sherlock, Oscar Tamburis, Manasa Tripathy, Filipa Ferreira, John Williams, F Hobbs.	373
The Relationship Between Demographic, Socioeconomic, and Health-Related Parameters and the Impact of COVID-19 on 24 Regions in India: Exploratory Cross-Sectional Study (e23083)	
Ravi Rajkumar.	394
Evaluating the Need for Routine COVID-19 Testing of Emergency Department Staff: Quantitative Analysis (e20260)	
Yuemei Zhang, Sheng-Ru Cheng.	403
Clinical Characteristics and Outcomes of Patients With Diabetes Admitted for COVID-19 Treatment in Dubai: Single-Centre Cross-Sectional Study (e22471)	
Rahila Bhatti, Amar Khamis, Samara Khatib, Seemin Shiraz, Glenn Matfin.	412
Characterizing Weibo Social Media Posts From Wuhan, China During the Early Stages of the COVID-19 Pandemic: Qualitative Content Analysis (e24125)	
Qing Xu, Ziyi Shen, Neal Shah, Raphael Cuomo, Mingxiang Cai, Matthew Brown, Jiawei Li, Tim Mackey.	422
Associations of Medications With Lower Odds of Typical COVID-19 Symptoms: Cross-Sectional Symptom Surveillance Study (e22521)	
Dietmar Urbach, Friedemann Awiszus, Sven Leiß, Tamsin Venton, Alexander Specht, Christian Apfelbacher.	437
An Epidemiological Model Considering Isolation to Predict COVID-19 Trends in Tokyo, Japan: Numerical Analysis (e23624)	
Motoaki Utamura, Makoto Koizumi, Seiichi Kirikami.	447

Anxiety and Sleep Disturbances Among Health Care Workers During the COVID-19 Pandemic in India: Cross-Sectional Online Survey ([e24206](#))
 Bhawna Gupta, Vyom Sharma, Narinder Kumar, Akanksha Mahajan. 466

Public Health Interventions' Effect on Hospital Use in Patients With COVID-19: Comparative Study ([e25174](#))
 Xiaofeng Wang, Rui Ren, Michael Kattan, Lara Jehi, Zhenshun Cheng, Kuangnan Fang. 488

Time Trends of the Public's Attention Toward Suicide During the COVID-19 Pandemic: Retrospective, Longitudinal Time-Series Study ([e24694](#))
 Dayle Burnett, Valsamma Eapen, Ping-I Lin. 499

SARS-CoV-2 Testing Service Preferences of Adults in the United States: Discrete Choice Experiment ([e25546](#))
 Rebecca Zimba, Sarah Kulkarni, Amanda Berry, William You, Chloe Mirzayi, Drew Westmoreland, Angela Parcesepe, Levi Waldron, Madhura Rane, Shivani Kochhar, McKaylee Robertson, Andrew Maroko, Christian Grov, Denis Nash. 509

A Racially Unbiased, Machine Learning Approach to Prediction of Mortality: Algorithm Development Study ([e22400](#))
 Angier Allen, Samson Mataraso, Anna Siefkas, Hoyt Burdick, Gregory Braden, R Dellinger, Andrea McCoy, Emily Pellegrini, Jana Hoffman, Abigail Green-Saxena, Gina Barnes, Jacob Calvert, Ritankar Das. 516

Perspective of an International Online Patient and Caregiver Community on the Burden of Spasticity and Impact of Botulinum Neurotoxin Therapy: Survey Study ([e17928](#))
 Atul Patel, Theodore Wein, Laxman Bahroo, Ophélie Wilczynski, Carl Rios, Manuel Murie-Fernández. 525

Review

Social Media as a Research Tool (SMaART) for Risky Behavior Analytics: Methodological Review ([e21660](#))
 Tavleen Singh, Kirk Roberts, Trevor Cohen, Nathan Cobb, Jing Wang, Kayo Fujimoto, Sahiti Myneni. 78

Corrigenda and Addenda

Correction Diagnostic Accuracy of Chest Computed Tomography Scans for Suspected Patients With COVID-19: Receiver Operating Characteristic Curve Analysis ([e25829](#))
 Lianpin Wu, Qike Jin, Jie Chen, Jiawei He, David Brett-Major, Jianghu Dong. 182

Letters to the Editor

Importance of Educating Teenagers on Appropriate Safety Gear for E-Scooters. Comment on "Follow-Up Investigation on the Promotional Practices of Electric Scooter Companies: Content Analysis of Posts on Instagram and Twitter" ([e18945](#))
 Claire SooHoo, Jackson SooHoo. 184

Errors in Tracing Coronavirus SARS-CoV-2 Transmission Using a Maximum Likelihood Tree. Comment on "A Snapshot of SARS-CoV-2 Genome Availability up to April 2020 and its Implications: Data Analysis" ([e23542](#))
 Peter Forster, Lucy Forster. 187



Authors' Reply to: Errors in Tracing Coronavirus SARS-CoV-2 Transmission Using a Maximum Likelihood Tree. Comment on "A Snapshot of SARS-CoV-2 Genome Availability up to April 2020 and its Implications: Data Analysis" ([e24661](#))
Carla Mavian, Simone Marini, Mattia Prosperi, Marco Salemi. 189

Viewpoints

Human-Animal Interaction and the Emergence of SARS-CoV-2 ([e22117](#))
Asma Hassani, Gulfaraz Khan. 232

Leveraging a Cloud-Based Critical Care Registry for COVID-19 Pandemic Surveillance and Research in Low- and Middle-Income Countries ([e21939](#))
CRIT Care Asia, Madiha Hashmi, Abi Beane, Srinivas Murthy, Arjen Dondorp, Rashan Haniffa. 388

Canada's Decentralized "Human-Driven" Approach During the Early COVID-19 Pandemic ([e20343](#))
Gregory Hansen, Amelie Cyr. 479

Editorial

Population Size Estimation Methods: Searching for the Holy Grail

Joyce J Neal¹, PhD, MPH; Dimitri Prybylski¹, PhD; Travis Sanchez², MPH, DVM; Wolfgang Hladik¹, MD, PhD

¹Epidemiology and Surveillance Branch, Division of Global HIV & TB, Center for Global Health, Centers for Disease Control and Prevention, Atlanta, GA, United States

²Rollins School of Public Health, Emory University, Atlanta, GA, United States

Corresponding Author:

Joyce J Neal, PhD, MPH

Epidemiology and Surveillance Branch, Division of Global HIV & TB

Center for Global Health

Centers for Disease Control and Prevention

1600 Clifton Road

Atlanta, GA, 30329

United States

Phone: 1 404 433 0184

Email: jxn4@cdc.gov

Abstract

Accurate size estimates of key populations (eg, sex workers, people who inject drugs, transgender people, and men who have sex with men) can help to ensure adequate availability of services to prevent or treat HIV infection; inform HIV response planning, target setting, and resource allocation; and provide data for monitoring and evaluating program outcomes and impact. A gold standard method for population size estimation does not exist, but quality of estimates could be improved by using empirical methods, multiple data sources, and sound statistical concepts. To highlight such methods, a special collection of papers in *JMIR Public Health and Surveillance* has been released under the title “Key Population Size Estimations.” We provide a summary of these papers to highlight advances in the use of empirical methods and call attention to persistent gaps in information.

(*JMIR Public Health Surveill* 2020;6(4):e25076) doi:[10.2196/25076](https://doi.org/10.2196/25076)

KEYWORDS

HIV; key populations; population size estimation; capture-recapture

Globally, most new HIV infections in 2019 were estimated to have occurred among key populations (KP), including sex workers, people who inject drugs (PWID), transgender people, and men who have sex with men (MSM), as well as their partners [1]. Worldwide, 62% of new HIV infections among adults were attributed to KP and their partners, ranging from 28% of new infections in eastern and southern Africa to 99% in Eastern Europe and central Asia [1]. Inferences such as these require not only robust analyses for the number of people living with HIV but also accurate size estimates for the various at-risk populations. For decades, population size estimation (PSE) has suffered from the lack of a gold standard method, leading to the use of numerous techniques and approaches with varying robustness and implemented with erratic fidelity [2]. Underestimates are believed to be common, but because we do not have actual population size counts, they are typically accepted and used for the sake of political expediency.

Accurate estimates of KP size are essential for understanding the scale of the response required to ensure adequate availability of services needed to prevent or treat HIV infection; to inform HIV response planning, target setting, and resource allocation;

and to provide data for monitoring and evaluating program outcomes and impact. For example, KP size estimates could help measure progress toward the Joint United Nations Programme on HIV/AIDS (UNAIDS) 95-95-95 goals (95% of HIV-positive individuals know their status; of these, 95% are receiving antiretroviral therapy; and of these, 95% are virally suppressed) [3]. However, the availability and quality of KP size estimates vary globally. Many countries have conducted PSE exercises, but results often are buried in surveillance reports (ie, these estimates may not be published in journals or presented at conferences) [4]. UNAIDS and the Centers for Disease Control and Prevention (CDC) have worked to compile data from PSE conducted as standalone studies or as part of biobehavioral surveys (BBS) [2,5,6]. Often, however, reported PSE are based on methods that are neither empirical (based on scientific, systematic observation or measurement) nor standardized and are not well documented. Furthermore, KP size is frequently reported as a point estimate without specifying measurements of statistical variability, such as confidence limits or credible intervals. Although estimates derived from nonempirical methods (ie, based on opinion or nonsystematic

observation) such as the Delphi method, wisdom of the crowds, and hotspot mapping may be useful for programmatic planning, more robust empirical PSE methods generally can be expected to facilitate better estimates of the number of KP members living with HIV (KPLHIV), yielding more representative and higher quality data [7,8] for use in measuring progress toward various targets, including percent of KPLHIV aware of their HIV status, percent of KPLHIV receiving antiretroviral treatment, and percent of those virally suppressed. The general population is relatively easy to enumerate using census methods, but estimating the size of KP faces several challenges: lack of a sampling frame, mobility or economic migration, and some KP members may not want to be counted (ie, they may choose to be less visible because of the stigma or criminalization of their KP-defining behaviors) [9,10]. In the absence of a gold-standard PSE method, methods that use empirical data, multiple data sources, and sound statistical concepts can be expected to provide more valid estimates than nonempirical methods.

Focused on application of empirical methods, a special collection of papers in *JMIR Public Health and Surveillance*

has been released under the title “Key Population Size Estimations” [11]. These 9 reports on empirically based PSE include innovative approaches, such as use of social media apps (Vietnam) [12], a reverse-tracking method (Namibia) [13], multiple-source capture-recapture (CRC; Uganda) [14], and successive sampling (SS)-PSE incorporating imputed visibility [15]. We provide a summary of these papers to highlight advances in the application of empirical methods and persisting gaps in information.

Almost all the papers (Table 1) presented estimates based on some form of CRC methodology — conventional two-source (2S)-CRC; multiple-source CRC; or service, unique object, unique event, or social app multiplier methods — or used prior estimates that may have been partially based on these methods for analysis (SS-PSE). Of the 9 papers, 4 described PSE embedded within a BBS [13,16-18], 1 described using datasets from previously conducted BBS [15], and 4 presented results from standalone PSE exercises [12,14,19,20].

Table 1. Population size estimation methods, key populations, and geographic location covered by papers in the special-themed issue.

Methods	Key population	Location	Citation
2S-CRC ^a	FSW ^b , MSM ^c	Uganda, 11 towns	19
2S-CRC	FSW (venue-based)	Vietnam, Ho Chi Minh City	20
Social app multiplier method	MSM	Vietnam, 12 provinces	12
3S-CRC ^d	FSW, MSM, PWID ^e	Uganda, Kampala	14
3S-CRC; multiplier method	FSW	South Sudan, 2 cities	16
Multiplier methods	FSW	South Africa, 3 cities	17
Multiplier methods, SS-PSE ^f	FSW, MSM/TGW ^g	Papua New Guinea, 3 cities	18
SS-PSE	FSW, MSM, PWID	Armenia, 3 cities	15
RTM ^h , RadR ⁱ	FSW	Namibia, 2 cities	13

^a2S-CRC: 2-source capture-recapture.

^bFSW: female sex workers.

^cMSM: men who have sex with men.

^d3S-CRC: 3-source capture-recapture.

^ePWID: people who inject drugs.

^fSS-PSE: successive sampling population size estimation.

^gTGW: transgender women.

^hRTM: reverse tracking method.

ⁱRadR: respondent-driven sampling-adjusted RTM.

Apodaca and colleagues [19] conducted a 2S-CRC in 11 small Ugandan towns with peers distributing unique objects to tag female sex workers (FSW) and MSM in the first capture. Distributors used a mobile global positioning system to record locations of the distribution for quality control purposes. A different group of peers (to minimize the risk of visiting the same venues again) collected data for the second capture, which consisted of asking FSW and MSM if they had received the unique object using 2 different recapture definitions: presentation of the object or identification of the object from a set of photos. The most credible results (compared with other published estimates) were based on presentation of the object.

Among the first empirically based PSE to be done in Uganda to obtain FSW and MSM size estimates at the small-town level, this exercise demonstrated the difference in results based on recapture definitions and the feasibility of using peers for data collection when provided proper training and standardized data collection tools.

To estimate the size of venue-based FSW in Ho Chi Minh City, Vietnam, Le et al [20] conducted multistage 2S-CRC. They used stratified probability proportionate to size to select districts, mapped venues, and distributed unique objects to all FSW in those venues. The recapture consisted of an equal probability

random selection of venues from the initial mapping and asking FSW in those venues if they had received the object. The PSE of venue-based FSW in these districts was multiplied by the inverse of the proportion of districts selected to calculate the number of venue-based FSW in Ho Chi Minh City. Although this PSE method is useful for venue-based KP, the authors note that estimates are needed for other FSW, including those who may seek clients using social media platforms.

Son et al [12] used a social media app multiplier method for PSE of MSM in 12 provinces in Vietnam. The first data source was the count of social app users, and the second source was data collected from MSM recruited via respondent-driven sampling (RDS) and who responded to an online questionnaire (telephone survey for MSM who did not have internet access). The PSE was derived by dividing the number of app users in a 1-month period by the proportion interviewed who reported using the app during the same period. Investigators estimated the size of the MSM population in 12 provinces, from which they extrapolated to generate a national PSE among MSM aged 15-49 years. This first attempt to estimate the MSM population in Vietnam empirically highlighted the feasibility of reaching many MSM through a social app and online. The percentage of men estimated to be MSM nationally (0.68%, 95% CI 0.46%-1.95%) is well below the published estimates for Southeast Asia of 3%-6% of MSM in the past 12 months [21]. PSE may have been underestimated by selecting users of only 1 social app, being biased toward those with higher internet or social app literacy, excluding MSM aged ≥ 50 years, and assuming that users of the social app during a 1-month period represented all MSM. Reported PSE may represent a minimum or a subgroup of MSM — some provinces had population proportions that were improbably low (eg, 0.21%). Future efforts should try to achieve better precision — wide confidence intervals included crude estimates previously derived by nonempirically based consensus methods. In one province, the PSE confidence interval ranged from about 4200 to 68,000, representing 0.6% to 9.6% of the male population aged 15-49 years. Adapting traditional empirical methods using social apps and web-based interviews, this method is quick and relatively inexpensive but needs improvement and additional validation.

In a study (published elsewhere) on the uptake of KP PSE in guiding HIV responses in Africa, Viswasam et al [4] described limited uptake of PSE in US President's Emergency Plan for AIDS Relief (PEPFAR) Country Operational Plans, national strategic health planning documents, and Global Fund Concept Notes and recommended stakeholder engagement and data-oriented capacity building. Two papers in this special-themed issue described implementation of multiplier methods in conjunction with BBS and the importance of stakeholder engagement in 3 South African cities among FSW [17] and in 3 Papua New Guinea cities among MSM, transgender women (TGW), and FSW [18]. Investigators in South Africa used unique object, unique event, and service multiplier methods; wisdom of the crowd; and a modified Delphi method to adopt consensus estimates [17]. Asserting that a PSE has limited value unless it is adopted and used by government, civil society, and global health funding partners, Grasso et al [17] found that stakeholder engagement and consensus were

critical to vetting and triangulating multiple empirically based estimates to ensure adoption and use of the PSE at the national and subnational levels. Because it is equally important not to allow political expediency or agendas to adjust what otherwise would be the best available PSE, data-oriented capacity building as promoted by Viswasam et al [4] may be essential to prevent the adoption of inferior PSE.

The Papua New Guinea PSE exercise, part of a BBS conducted among MSM and TGW (combined) and FSW, employed unique object and service multiplier methods as well as SS-PSE [18]. As in South Africa, final estimates were chosen through meetings among experts that were then presented to key stakeholders for adoption of a single estimate in each city. Authors highlighted the challenges in using these methods — the wide variation in results and importance in understanding the biases in data collection, including issues with the availability and quality of HIV-service data.

Doshi et al [14] demonstrated the feasibility of using 3-source (3S)-CRC as a standalone (ie, not done in conjunction with a survey) method for PSE in a resource-limited setting [14]. One of the benefits of 3S-CRC is the ability to account partially for sample dependencies (thereby relaxing the assumption of independence required by 2S-CRC methods) by allowing sources to be examined pairwise. In this first use of 3S-CRC for FSW, MSM, and PWID in Kampala, Uganda, the project team distributed 2 different unique objects in each of the first 2 captures, C1 and C2. KP members were asked in C2 and C3 whether they received the objects distributed in C1 and C2. The number in C3 receiving one or both objects was determined. Among PWID, recording errors prevented use of data collected in C3; however, data from C1 and C2 could be analyzed as conventional 2S-CRC. PSE were derived using the Lincoln-Petersen method for 2S-CRC (PWID) and a Bayesian nonparametric latent-class model for 3S-CRC (MSM and FSW). For the latter, statistical analyses were performed in R using the Bayesian nonparametric latent-class capture-recapture package (LCMCR). Use of LCMCR was innovative because this approach was not originally developed for analyzing epidemiologic data.

Okiria et al [16] also described exercises undertaken in conjunction with a BBS to estimate the number of FSW in the South Sudan capital city, Juba, and Nimule, on the South Sudan-Uganda border. They used unique object and service multiplier methods as well as 3S-CRC. The attempt to conduct 3S-CRC in Juba was thwarted when the third capture, delayed because of unique object procurement issues, was conducted 6 months after the BBS data collection had concluded and did not include questions needed to determine the number of individuals in each capture separately. Therefore, analysis was treated the same as for a routine unique object multiplier method. In Nimule, they found divergent PSE across all methods and postulated violation of the closed population assumption because of displacement of FSW due to conflict that delayed BBS launch for 6 months. Furthermore, some results generated implausible FSW population proportions (ie, as high as 193%), possibly due to many FSW not actually residing in Nimule but across the border in Uganda. Lessons learned included the need to improve data quality during collection (eg, ensuring correct

identification of residency and deduplication of service records) and timing the first 2 captures before the BBS (if BBS is used as a data source) to ensure individual-level data can be more accurately collected by interviewers who receive intensive training compared with volunteer object distributors. Despite conflict and logistical and operational challenges, investigators demonstrated the feasibility of conducting 3S-CRC and found that use of multiple methods to estimate the number of people not easily counted during mapping improved PSE compared with previous results.

To advance the SS-PSE method [22], McLaughlin et al [15] examined the performance of a modification that allows visibility to be jointly modeled with population size. Imputed visibility is a measure of how likely persons are to participate in an RDS survey [23]. This measure may be used instead of self-reported social network size, which is usually considered a proxy for inclusion probability. Using 15 datasets from RDS surveys of FSW, MSM, and PWID from 3 cities in Armenia, they compared and evaluated the accuracy of imputed visibility PSE against those found for the same populations based on other methods. The imputed visibility adjustment worked well with great (as defined by authors) fits with prior estimation for FSW and PWID, but MSM populations in all 3 cities had inconsistencies with expert prior values that made a great fit impossible. Authors cautioned that prior estimations from expert opinions may not always be accurate and that SS-PSE be used only after ensuring that RDS assumptions have been met, convergence has been reached on primary endpoints, and the sampled population network structure does not have bottlenecks. Lastly, to ensure generation of the most accurate estimates, they recommended that SS-PSE be used in conjunction with other PSE commonly used in RDS surveys as well as with other years of SS-PSE.

Wesson et al [13] described using an RDS adjustment (respondent-driven sampling-adjusted [RadR]) to the less-commonly used reverse tracking method (RTM) [24] to estimate the population size of FSW in Namibia [13]. The RadR method allows for application in RDS surveys and improves upon venue-based RTM because RaDR-based results account for the proportion of KP that do not congregate at venues and thus should provide more representative PSE. Additionally, RadR can adjust for double-counting associated with traditional venue-based RTM. The novel RadR method was successfully integrated with RDS surveys among FSW in 2 sites in Windhoek, Namibia to provide plausible PSE estimates compatible with the Namibia Ministry of Health and Social Services official estimates based on triangulation of PSE derived from multiple methods. This study demonstrated that, although it still needs more field testing with other KP groups and in other geographical settings, the RadR method is easy to integrate into RDS surveys and might be a promising methodological advance.

Of the 9 papers in this collection, 8 papers described PSE of FSW, 2 reported on PWID, and 5 included MSM (of these, 1 combined TGW with MSM). TGW PSE are lacking globally [2,4-6,8]. Viswasam et al [4] conducted a review of all PSE for KP in 54 African countries from 2009 through 2017 and identified 118 size estimates — 70 for FSW, 27 for MSM, 21

for PWID, and none for transgender persons. PSE frequently combines TGW with MSM; because the 2 populations have distinct needs, generating separate estimates will be crucial for advocating for both KPs and appropriately targeted programs and services. Although only 2 papers in this collection reported PWID size estimates [14,15], many countries have included or are planning to include PSE in their BBS among PWID [25,26; personal communication]. Estimating the size of the PWID population may be less challenging in areas with substantial drug-injecting activity, for example, along drug transportation routes and border areas. A dearth of size estimates for the female PWID population argues for enhancing efforts to recruit female PWID for BBS and PSE. Challenges to estimating population size of FSW include their mobility, driven by economic needs and opportunity, and the variety of settings in which they work or find clients, including the increasing use of internet sites and social media apps. Social media and dating apps are emerging as a data source for PSE, especially among MSM [12,27], but should be used with caution. Limitations of social media and dating apps for size estimation include potential overcounting if many users are allies or onlookers and not members of the KP and if identification and deduplication of users with multiple accounts are not possible; dependence on internet and smart phone coverage; variability of app use by age and cultural context; and unstable popularity of apps as new apps are introduced and adopted. Furthermore, detailed information about how social apps derive estimated number of users and classify user characteristics may be unknown or undisclosed to protect proprietary interests.

Publications of KP PSE report the estimated absolute number of KP but frequently omit the KP population proportion. This metric, however, provides a reality check to assess underestimation or overestimation by comparison with other published estimates [5,6,8,21,28]. For example, 1.5% may be a reasonable minimum threshold for an urban MSM population proportion — figures less than 1.5% suggest underestimation. The proportion of the population who are KP members will vary by characteristics (eg, urbanicity, border, transportation routes, drug trafficking routes, economic opportunity). The proportion of the population that is MSM or TGW probably is the most stable compared with that for PWID or FSW, which is more variable and localized. The principal challenge, however, is to account for MSM mobility (ie, migration from rural to urban areas and to an unknown extent, small-to-larger town migration). Hence, the proportion of MSM among urban men can and should be expected to be higher as they absorb MSM from rural and small-town settings.

Countries are encouraged to publish PSE reports in the peer-reviewed literature, in addition to including estimates in their surveillance reports or reporting estimates to UNAIDS and other agencies upon request. Even when published, however, Viswasam and colleagues [4] noted that there remains “limited evidence of sustained uptake of these data to guide the HIV responses.” In another review of the available and quality of KP size estimates, Sabin et al [2] concluded that size estimates are “increasingly available but quality varies widely” and that “different approaches present challenges for data use.” This collection of papers provides examples of PSE reports that may

serve as models for countries to use to publish their own results. We recommend that countries use multiple, robust empirical methods; document the process; synthesize results; report point estimates with confidence or credible intervals; include population proportions (using appropriate sex-specific, age-specific, and location-specific census data); and take steps to ensure uptake and use of estimates to guide the HIV response toward ending the HIV epidemic among KP.

Numerous challenges remain, including the aforementioned need for distinct PSE for TGW and female PWID. If a BBS is

deemed impractical because of relatively small population sizes or lack of resources, standalone PSE exercises as described in 4 of the papers [12,14,19,20] presented in this special-themed issue (described earlier) may be considered to fill these gaps. We continue to seek new, innovative, or improved methods in a search for the holy grail (ie, a gold standard for finding the true population size). In addition to encouraging publication and use of high-quality PSE, we underscore the need for a global consensus on minimum-threshold PSE to prevent the use of extreme underestimates and highlight the continued need for operational research to advance empirically based PSE.

Acknowledgments

This publication has been supported by the PEPFAR through the CDC. The findings and conclusions in this editorial are those of the authors and do not necessarily represent the official position of the funding agencies.

Conflicts of Interest

None declared.

References

1. UNAIDS Data 2020. Joint United Nations Programme on HIV/AIDS. 2020 Jul 06. URL: <https://www.unaids.org/en/resources/documents/2020/unaids-data> [accessed 2020-07-08]
2. Sabin K, Zhao J, Garcia Calleja JM, Sheng Y, Arias Garcia S, Reinisch A, et al. Availability and Quality of Size Estimations of Female Sex Workers, Men Who Have Sex with Men, People Who Inject Drugs and Transgender Women in Low- and Middle-Income Countries. *PLoS One* 2016 May 10;11(5):e0155150 [FREE Full text] [doi: [10.1371/journal.pone.0155150](https://doi.org/10.1371/journal.pone.0155150)] [Medline: [27163256](https://pubmed.ncbi.nlm.nih.gov/27163256/)]
3. Fast-track: Ending the AIDS epidemic by 2030. Joint United Nations Programme on HIV/AIDS (UNAIDS). 2014. URL: https://www.unaids.org/sites/default/files/media_asset/JC2686_WAD2014report_en.pdf [accessed 2020-05-22]
4. Viswasam N, Lyons C, MacAllister J, Millett G, Sherwood J, Rao A, Global HIV Research Group. The uptake of population size estimation studies for key populations in guiding HIV responses on the African continent. *PLoS One* 2020;15(2):e0228634 [FREE Full text] [doi: [10.1371/journal.pone.0228634](https://doi.org/10.1371/journal.pone.0228634)] [Medline: [32101551](https://pubmed.ncbi.nlm.nih.gov/32101551/)]
5. The Key Populations Atlas. UNAIDS. 2018. URL: <http://www.aidsinfoonline.org/kpatlas/#/home> [accessed 2020-11-16]
6. Avenir Health. Quick Start Guide for Spectrum. Glastonbury, CT: Avenir Health; 2019.
7. Larney S, Leung J, Grebely J, Hickman M, Vickerman P, Peacock A, et al. Global systematic review and ecological analysis of HIV in people who inject drugs: National population sizes and factors associated with HIV prevalence. *Int J Drug Policy* 2020 Mar;77:102656 [FREE Full text] [doi: [10.1016/j.drugpo.2019.102656](https://doi.org/10.1016/j.drugpo.2019.102656)] [Medline: [31951926](https://pubmed.ncbi.nlm.nih.gov/31951926/)]
8. Degenhardt L, Peacock A, Colledge S, Leung J, Grebely J, Vickerman P, et al. Global prevalence of injecting drug use and sociodemographic characteristics and prevalence of HIV, HBV, and HCV in people who inject drugs: a multistage systematic review. *Lancet Glob Health* 2017 Dec;5(12):e1192-e1207 [FREE Full text] [doi: [10.1016/S2214-109X\(17\)30375-3](https://doi.org/10.1016/S2214-109X(17)30375-3)] [Medline: [29074409](https://pubmed.ncbi.nlm.nih.gov/29074409/)]
9. Heckathorn DD. Respondent-Driven Sampling: A New Approach to the Study of Hidden Populations. *Social Problems* 1997 May;44(2):174-199. [doi: [10.2307/3096941](https://doi.org/10.2307/3096941)]
10. Kitts J. Egocentric Bias or Information Management? Selective Disclosure and the Social Roots of Norm Misperception. *Social Psychology Quarterly* 2003 Sep;66(3):222-237 [FREE Full text] [doi: [10.2307/1519823](https://doi.org/10.2307/1519823)]
11. e-Collection: CDC Theme Issue: Key Population Size Estimations. *JMIR Public Health and Surveillance*. 2018. URL: <https://publichealth.jmir.org/themes/578> [accessed 2020-05-26]
12. Son V, Safarnejad A, Nga N, Linh VM, Tu LTC, Manh PD, et al. Estimation of the Population Size of Men Who Have Sex With Men in Vietnam: Social App Multiplier Method. *JMIR Public Health Surveill* 2019 Apr 17;5(2):e12451 [FREE Full text] [doi: [10.2196/12451](https://doi.org/10.2196/12451)] [Medline: [30994469](https://pubmed.ncbi.nlm.nih.gov/30994469/)]
13. Wesson PD, Adhikary R, Jonas A, Gerndt K, Mirzazadeh A, Katuta F, et al. Estimating the Population Size of Female Sex Workers in Namibia Using a Respondent-Driven Sampling Adjustment to the Reverse Tracking Method: A Novel Approach. *JMIR Public Health Surveill* 2019 Mar 14;5(1):e11737 [FREE Full text] [doi: [10.2196/11737](https://doi.org/10.2196/11737)] [Medline: [30869646](https://pubmed.ncbi.nlm.nih.gov/30869646/)]
14. Doshi R, Apodaca K, Ogwal M, Bain R, Amene E, Kiyingi H, et al. Correction: Estimating the Size of Key Populations in Kampala, Uganda: 3-Source Capture-Recapture Study. *JMIR Public Health Surveill* 2020 May 12;6(2):e19893 [FREE Full text] [doi: [10.2196/19893](https://doi.org/10.2196/19893)] [Medline: [32396517](https://pubmed.ncbi.nlm.nih.gov/32396517/)]

15. McLaughlin K, Johnston L, Gamble L, Grigoryan T, Papoyan A, Grigoryan S. Population Size Estimations Among Hidden Populations Using Respondent-Driven Sampling Surveys: Case Studies From Armenia. *JMIR Public Health Surveill* 2019 Mar 14;5(1):e12034 [FREE Full text] [doi: [10.2196/12034](https://doi.org/10.2196/12034)] [Medline: [30869650](https://pubmed.ncbi.nlm.nih.gov/30869650/)]
16. Okiria A, Bolo A, Achut V, Arkangelo GC, Michael ATI, Katoro JS, et al. Novel Approaches for Estimating Female Sex Worker Population Size in Conflict-Affected South Sudan. *JMIR Public Health Surveill* 2019 Mar 18;5(1):e11576 [FREE Full text] [doi: [10.2196/11576](https://doi.org/10.2196/11576)] [Medline: [30882356](https://pubmed.ncbi.nlm.nih.gov/30882356/)]
17. Grasso M, Manyuchi A, Sibanyoni M, Marr A, Osmand T, Isdahl Z, et al. Estimating the Population Size of Female Sex Workers in Three South African Cities: Results and Recommendations From the 2013-2014 South Africa Health Monitoring Survey and Stakeholder Consensus. *JMIR Public Health Surveill* 2018 Aug 07;4(3):e10188 [FREE Full text] [doi: [10.2196/10188](https://doi.org/10.2196/10188)] [Medline: [30087089](https://pubmed.ncbi.nlm.nih.gov/30087089/)]
18. Weikum D, Kelly-Hanku A, Hou P, Kupul M, Amos-Kuma A, Badman SG, et al. Kuantim mi tu ("Count me too"): Using Multiple Methods to Estimate the Number of Female Sex Workers, Men Who Have Sex With Men, and Transgender Women in Papua New Guinea in 2016 and 2017. *JMIR Public Health Surveill* 2019 Mar 21;5(1):e11285 [FREE Full text] [doi: [10.2196/11285](https://doi.org/10.2196/11285)] [Medline: [30896432](https://pubmed.ncbi.nlm.nih.gov/30896432/)]
19. Apodaca K, Doshi R, Ogwal M, Kiyangi H, Aluzimbi G, Musunguzi G, et al. Capture-Recapture Among Men Who Have Sex With Men and Among Female Sex Workers in 11 Towns in Uganda. *JMIR Public Health Surveill* 2019 Apr 03;5(2):e12316 [FREE Full text] [doi: [10.2196/12316](https://doi.org/10.2196/12316)] [Medline: [30942697](https://pubmed.ncbi.nlm.nih.gov/30942697/)]
20. Le G, Khuu N, Tieu V, Nguyen PD, Luong HTY, Pham QD, et al. Population Size Estimation of Venue-Based Female Sex Workers in Ho Chi Minh City, Vietnam: Capture-Recapture Exercise. *JMIR Public Health Surveill* 2019 Jan 29;5(1):e10906 [FREE Full text] [doi: [10.2196/10906](https://doi.org/10.2196/10906)] [Medline: [30694204](https://pubmed.ncbi.nlm.nih.gov/30694204/)]
21. Cáceres C, Konda K, Pecheny M, Chatterjee A, Lyerla R. Estimating the number of men who have sex with men in low and middle income countries. *Sex Transm Infect* 2006 Jun;82 Suppl 3:iii3-iii9 [FREE Full text] [doi: [10.1136/sti.2005.019489](https://doi.org/10.1136/sti.2005.019489)] [Medline: [16735290](https://pubmed.ncbi.nlm.nih.gov/16735290/)]
22. Handcock M, Gile K, Mar C. Estimating the size of populations at high risk for HIV using respondent-driven sampling data. *Biometrics* 2015 Mar;71(1):258-266 [FREE Full text] [doi: [10.1111/biom.12255](https://doi.org/10.1111/biom.12255)] [Medline: [25585794](https://pubmed.ncbi.nlm.nih.gov/25585794/)]
23. McLaughlin KR, Handcock M, Johnston L. Inference for the visibility distribution for respondent-driven sampling. *JSM Proceeding*. Alexandria, VA: American Statistical Association; 2015. URL: <https://pdfs.semanticscholar.org/f99f/9816e463cb8081562aff3d0b5d527c5ddffd.pdf> [accessed 2020-07-28]
24. Vadivoo S, Gupte MD, Adhikary R, Kohli A, Kangusamy B, Joshua V, IBBA Study Team. Appropriateness and execution challenges of three formal size estimation methods for high-risk populations in India. *AIDS* 2008 Dec;22 Suppl 5:S137-S148. [doi: [10.1097/01.aids.0000343772.82647.2d](https://doi.org/10.1097/01.aids.0000343772.82647.2d)] [Medline: [19098474](https://pubmed.ncbi.nlm.nih.gov/19098474/)]
25. Karimov S, Sayburkhonov D, Boymurodov K, Deryabina A, Ivakin V, Nabijonov A. Report on the results of integrated bio-behavioral study on HIV and estimation of the number of sex workers and people who inject drugs in the Republic of Tajikistan, 2018. Dushanbe 2019.
26. National AP. National AIDS Program, Ministry of Health and Sports Myanmar. 2019 Jan. URL: <https://www.aidsdatahub.org/sites/default/files/resource/myanmar-ibbs-and-population-size-estimates-among-pwid-2017-2018.pdf>
27. Baral S, Turner R, Lyons C, Howell S, Honermann B, Garner A, et al. Population Size Estimation of Gay and Bisexual Men and Other Men Who Have Sex With Men Using Social Media-Based Platforms. *JMIR Public Health Surveill* 2018 Feb 08;4(1):e15 [FREE Full text] [doi: [10.2196/publichealth.9321](https://doi.org/10.2196/publichealth.9321)] [Medline: [29422452](https://pubmed.ncbi.nlm.nih.gov/29422452/)]
28. Vandepitte J, Lyerla R, Dallabetta G, Crabbé F, Alary M, Buvé A. Estimates of the number of female sex workers in different regions of the world. *Sex Transm Infect* 2006 Jun;82 Suppl 3:iii18-iii25 [FREE Full text] [doi: [10.1136/sti.2006.020081](https://doi.org/10.1136/sti.2006.020081)] [Medline: [16735288](https://pubmed.ncbi.nlm.nih.gov/16735288/)]

Abbreviations

- 2S-CRC:** 2-source capture-recapture
- 3S-CRC:** 3-source capture-recapture
- BBS:** biobehavioral surveys
- CDC:** Centers for Disease Control and Prevention
- FSW:** female sex workers
- KP:** key populations
- KPLHIV:** key populations living with HIV
- LCMCR:** latent-class capture-recapture package
- MSM:** men who have sex with men
- PEPFAR:** President's Emergency Plan for AIDS Relief
- PSE:** population size estimation
- PWID:** people who inject drugs
- RadR:** respondent-driven sampling-adjusted reverse tracking method
- RDS:** respondent-driven sampling

RTM: reverse tracking method

SS-PSE: successive sampling population size estimation

TGW: transgender women

UNAIDS: Joint United Nations Programme on HIV/AIDS

Edited by G Eysenbach; submitted 16.10.20; this is a non-peer-reviewed article; accepted 30.10.20; published 03.12.20.

Please cite as:

Neal JJ, Prybylski D, Sanchez T, Hladik W

Population Size Estimation Methods: Searching for the Holy Grail

JMIR Public Health Surveill 2020;6(4):e25076

URL: <http://publichealth.jmir.org/2020/4/e25076/>

doi: [10.2196/25076](https://doi.org/10.2196/25076)

PMID: [33270035](https://pubmed.ncbi.nlm.nih.gov/33270035/)

©Joyce J Neal, Dimitri Prybylski, Travis Sanchez, Wolfgang Hladik. Originally published in JMIR Public Health and Surveillance (<http://publichealth.jmir.org>), 03.12.2020. This is an open-access article distributed under the terms of the Creative Commons Attribution License (<https://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in JMIR Public Health and Surveillance, is properly cited. The complete bibliographic information, a link to the original publication on <http://publichealth.jmir.org>, as well as this copyright and license information must be included.

Original Paper

Availability and Quality of Surveillance and Survey Data on HIV Prevalence Among Sex Workers, Men Who Have Sex With Men, People Who Inject Drugs, and Transgender Women in Low- and Middle-Income Countries: Review of Available Data (2001-2017)

Sonia Arias Garcia^{1*}, MSc; Jia Chen^{2*}, MSc; Jesus Garcia Calleja³, MD; Keith Sabin¹, PhD; Chinelo Ogbuanu⁴, MD, PhD; David Lowrance³, MD; Jinkou Zhao^{4,5,6}, MSc, PhD, MD

¹Joint United Nations Programme on HIV/AIDS, Geneva, Switzerland

²School of Public Health, Xiamen University, Xiamen, China

³World Health Organization, Geneva, Switzerland

⁴The Global Fund to Fight AIDS, Tuberculosis and Malaria, Grand-Saconnex, Geneva, Switzerland

⁵Center for Global Health, School of Public Health, Nanjing Medical University, Nanjing, China

⁶Jiangsu Provincial Center for Disease Control and Prevention, Nanjing, China

*these authors contributed equally

Corresponding Author:

Jinkou Zhao, MSc, PhD, MD

The Global Fund to Fight AIDS, Tuberculosis and Malaria

Chemin du Pommier 40

Grand-Saconnex, Geneva, 1218

Switzerland

Phone: 41 794117847

Email: jinkou.zhao@theglobalfund.org

Abstract

Background: In 2019, 62% of new HIV infections occurred among key populations (KPs) and their sexual partners. The World Health Organization (WHO) recommends implementation of bio-behavioral surveys every 2-3 years to obtain HIV prevalence data for all KPs. However, the collection of these data is often less frequent and geographically limited.

Objective: This study intended to assess the availability and quality of HIV prevalence data among sex workers (SWs), men who have sex with men (MSM), people who inject drugs, and transgender women (transwomen) in low- and middle-income countries.

Methods: Data were obtained from survey reports, national reports, journal articles, and other grey literature available to the Global Fund, Joint United Nations Programme on HIV/AIDS, and WHO or from other open sources. Elements reviewed included names of subnational units, HIV prevalence, sampling method, and size. Based on geographical coverage, availability of trends over time, and recency of estimates, data were categorized by country and grouped as follows: nationally adequate, locally adequate but nationally inadequate, no recent data, no trends available, and no data.

Results: Among the 123 countries assessed, 91.9% (113/123) presented at least 1 HIV prevalence data point for any KP; 78.0% (96/123) presented data for at least 2 groups; and 51.2% (63/123), for at least 3 groups. Data on all 4 groups were available for only 14.6% (18/123) of the countries. HIV prevalence data for SWs, MSM, people who inject drugs, and transwomen were available in 86.2% (106/123), 80.5% (99/123), 45.5% (56/123), and 23.6% (29/123) of the countries, respectively. Only 10.6% (13/123) of the countries presented nationally adequate data for any KP between 2001 and 2017; 6 for SWs; 2 for MSM; and 5 for people who inject drugs. Moreover, 26.8% (33/123) of the countries were categorized as locally adequate but nationally inadequate, mostly for SWs and MSM. No trend data on SWs and MSM were available for 38.2% (47/123) and 43.9% (54/123) of the countries, respectively, while no data on people who inject drugs and transwomen were available for 76.4% (94/123) and 54.5% (67/123) of the countries, respectively. An increase in the number of data points was observed for MSM and transwomen. Overall increases were noted in the number and proportions of data points, especially for MSM, people who inject drugs, and transwomen, with sample sizes exceeding 100.

Conclusions: Despite general improvements in health data availability and quality, the availability of HIV prevalence data among the most vulnerable populations in low- and middle-income countries remains insufficient. Data collection should be expanded to include behavioral, clinical, and epidemiologic data through context-specific differentiated survey approaches while emphasizing data use for program improvements. Ending the HIV epidemic by 2030 is possible only if the epidemic is controlled among KPs.

(*JMIR Public Health Surveill* 2020;6(4):e21688) doi:[10.2196/21688](https://doi.org/10.2196/21688)

KEYWORDS

Key populations; HIV prevalence; men who have sex with men; people who inject drugs; sex workers; transgender women; low- and middle-income countries

Introduction

The prevalence of infection and disease and their distribution over time are the most fundamental elements of information required to describe an epidemic and its response. The risk of transmitting HIV varies across individuals, subpopulations, and communities. The overall risk is based on a combination of prevalence levels, behaviors, and health services, and is associated with differential transmission and acquisition risks and interactions between different populations. Globally, in 2019, an estimated 62% of new HIV infections occurred among stigmatized, epidemiologically key populations (KPs) and their sexual partners [1]. KPs are defined groups who, due to specific higher risk behaviors, are at increased risk of HIV irrespective of the epidemic type or local context [2]. In addition, their behaviors are often related to legal and social issues, such as stigma. They also experience reduced access to quality and essential health services, such as pre-exposure prophylaxis and antiretroviral treatment, further increasing their HIV acquisition and transmission risk [3]. The relative risk of acquiring HIV among gay men and other men who have sex with men (MSM) is 26 times higher than that among heterosexual men. This risk is 29 and 30 times higher, respectively, for people who inject drugs compared to those who do not inject drugs and sex workers (SWs) aged 15-49 years than same-aged females who do not sell sex. Transgender women (transwomen) are 13 times more likely than adults aged 15-49 years to acquire HIV [1]. Globally, MSM, people who inject drugs, and SWs accounted for 23%, 10%, and 8% of all new HIV infections in 2019 [1].

The geographic distribution of risks for acquiring and transmitting HIV is heterogeneous. Injection drug use and sex work occur more frequently in urban areas or areas with better economic development opportunities, though they are not absent from rural areas [4,5]. In many countries, MSM and transwomen migrate to urban areas in an attempt to leave behind repressive social stigma and discrimination [6]. Thus, spatial distribution of risks and HIV prevalence is complex across and within countries, and geographic mobility poses a unique challenge to health service continuities. It is impractical to implement surveillance and survey activities that can be used to generate prevalence estimates for all relevant subnational units (SNUs) within a country. However, for HIV prevention, care and treatment programming must be implemented efficiently so as to achieve a population-level impact, and a good understanding of the distribution of HIV infections among and across communities is required. The absence of HIV prevalence data

among a specific KP is often the result of either the lack of appreciation that a population is affected differently at the local level due to its risk profile, or the refusal to recognize the existence of a specific KP. The omission of a surveillance approach that includes information on HIV prevalence among KPs can be attributed to structural stigma and discrimination toward these populations [7]. Latent or blatant structural stigma and discrimination toward KPs obstruct progress in the HIV response, including the 95-95-95 targets and impact goals. The behavioral characteristics that define each KP may not have been formally recognized at one time or another in all countries [8].

In many countries, HIV prevalence data have been collected among KPs since the late 1980s. Typically, HIV sentinel surveys were established in cities. Sentinel survey activities have continued in some countries and locales without pause over the ensuing 30 years, while others have stopped for various reasons [9]. Today, more than 120 countries report routine sentinel surveillance or surveys among 1 or more KPs. The number and periodicity of surveys over time, preferably using consistent methods and producing data amenable to analysis, can vary widely. Trend analysis, in particular, must consider the periodicity and recency of available data as well as the number or proportion of SNUs from which the data have been generated.

Although the World Health Organization (WHO) guidelines [10] recommend that bio-behavioral surveys (BBS) be implemented every 2-3 years in all relevant KPs and in all appropriate geographic areas within a country, in practice, many countries conduct BBS periodically, as resources allow. Irrespective of whether the country conducts sentinel surveillance surveys or more intensive BBS, even the most complete models include at least 1 site in the capital of each province. However, almost no data exist beyond the provincial capitals. Furthermore, some countries rely on sporadically collected data and, at times, from only 1 city. These data, regardless of the often-limited number and distribution of SNUs from which they have been generated, are frequently used as the basis for national estimates and a planning resource for a country's national epidemic response. In each case, assumptions must be made about the distribution of HIV infections, and some form of extrapolation is necessary to estimate the burden of HIV among KPs at the national level.

Another important consideration involves the quality of individual survey results used for generating HIV estimates. A good quality survey will provide valid estimates that are statistically representative of the population being surveyed.

Representativeness is a challenge for surveys among KPs due to the absence of a sampling frame [10]. Sentinel surveillance often involved convenience sampling in the 1990s and early 2000s. In such cases, the methodological consistency and trend analysis of HIV prevalence outweigh the representativeness. More recent surveys applied approximate probability sampling, such as respondent-driven sampling (RDS) and time-location sampling (TLS) [11].

Some efforts have been made to assess HIV prevalence data with similar parameters, such as KP groups, survey sites, HIV prevalence, sample size, and sampling method, among KPs at the regional level [12-18]. Most addressed a specific region or group, or covered a shorter period. Additionally, systematic assessment methods were not reported. The present analysis provides a complete and extensive review of the HIV prevalence studies/reports among KPs from 2001 to 2017. We describe the availability and quality of HIV prevalence data among KPs in 123 low- and middle-income countries, which account for more than 90% of the estimated global population living with HIV in 2019 [1]. Similar assessment methods for the availability and quality of population size estimates were published in 2016 [19].

Methods

Data Sources and Elements

We examined a variety of health research sources for published and unpublished literature that included HIV prevalence data for each of the 4 aforementioned KPs, namely MSM, SWs, people who inject drugs, and transwomen.

The following data sources were examined, irrespective of their language: Country Progress Reports for the United Nations General Assembly Special Session on AIDS; Global AIDS Response Progress Reports or Global AIDS Monitoring reports submitted to the Joint United Nations Programme on HIV/AIDS (UNAIDS); AIDS Data Hub [20]; annexes to Global Fund concept notes, funding requests, and programmatic gap analysis tables contained therein; and publicly available documents, including integrated BBS or sentinel surveillance reports; journal articles available on PubMed; grey literature available on websites; and technical meeting abstracts, such as those at International AIDS Conference sites. The terms used to search the publicly available documents included “key populations,” “most at-risk populations,” “risk groups,” “men who have sex with men,” “gay,” “gay men,” “sex workers,” “female sex

workers,” “male sex workers,” “transgender sex workers,” “transgender,” “transgender women,” “transwomen,” “injecting drug users,” “injection drug users,” “drug users,” and “people who inject drugs.” Acronyms, including “MSM,” “FSW,” “MSW,” “TG,” “PWID,” and “IDU,” and their variations in different languages were also utilized. The main languages used in the search were English, Spanish, French, Portuguese, Russian, and Chinese. In addition, we abstracted data from reports in Arabic, Nepali, and Farsi. The assessment was limited to 123 countries that were eligible for funding from the Global Fund after the introduction of its new funding model in 2014 [21].

The reports were obtained either directly from UNAIDS or the Global Fund. The obtained reports and articles were utilized in the following priority order: (1) Reports submitted to UNAIDS or the Global Fund by funded countries, either in a draft or the final format, (2) journal articles, and (3) other grey literature available online. In case an article was based on a submitted report, we obtained the information from the report.

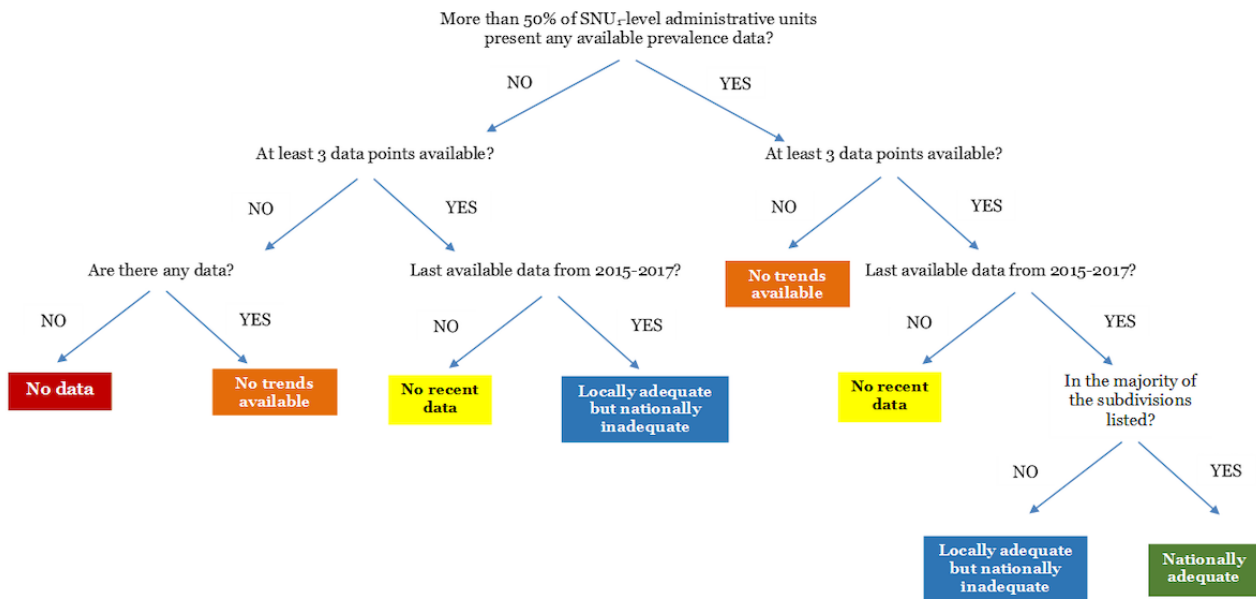
UNAIDS, WHO, and the Global Fund utilize a common systematic mapping approach based on abstraction of standard metadata from each survey report from 2001 onwards. This approach was used on all surveys conducted between 2001 and 2017 to conduct a basic quality assessment, and it included the name of the site, HIV prevalence, sampling method, and sample size. The survey or sentinel surveillance had to have been conducted between 2001 and 2017 for the data to be included in the assessment. The year in which the survey or sentinel surveillance was completed was used. When the survey or sentinel surveillance completion date was not available, the publication date was used as a proxy. The first-order of subnational administrative units (SNU1), available from the World Factbook [22], such as province, region, or state, were used to compare the distribution of the survey or sentinel surveillance sites to define the geographic coverage.

An initial review/analysis of all the studies meeting the aforementioned criteria was conducted in December 2016 and later updated in July 2018.

Categorization and Scoring

All the HIV prevalence data were categorized by country and KP group regarding availability and quality in descending order from (1) to (5) according to criteria that considered the geographical coverage, availability of trends over time, and recency of estimates (Figure 1).

Figure 1. Decision tree depicting categorization of the subnational HIV prevalence data by key population and country. SNU₁: first-order subnational administrative unit, such as a province, state, or region.



(1) Nationally adequate: This category comprised countries with more than 50% of SNU₁-level administrative units presenting any available prevalence data, with most having at least 3 data points, the last one between 2015 and 2017.

(2) Locally adequate within selected SNUs but nationally inadequate: This category comprised two scenarios, namely

(a) countries with less than 50% of SNU₁-level administrative units with any data, with the majority having at least 3 data points, the last one between 2015 and 2017, or

(b) countries with more than 50% of SNU₁-level administrative units with any data, with the majority not meeting the criteria of having at least 3 data points, the last one between 2015 and 2017.

(3) No recent data: This category comprised countries with at least 3 available data points for one or more of the SNUs listed, but the last data point was collected prior to 2015.

(4) No trends available: This category comprised countries with less than 3 available data points for any SNU.

(5) No data: This category comprised countries with no HIV prevalence data for any KPs since 2001.

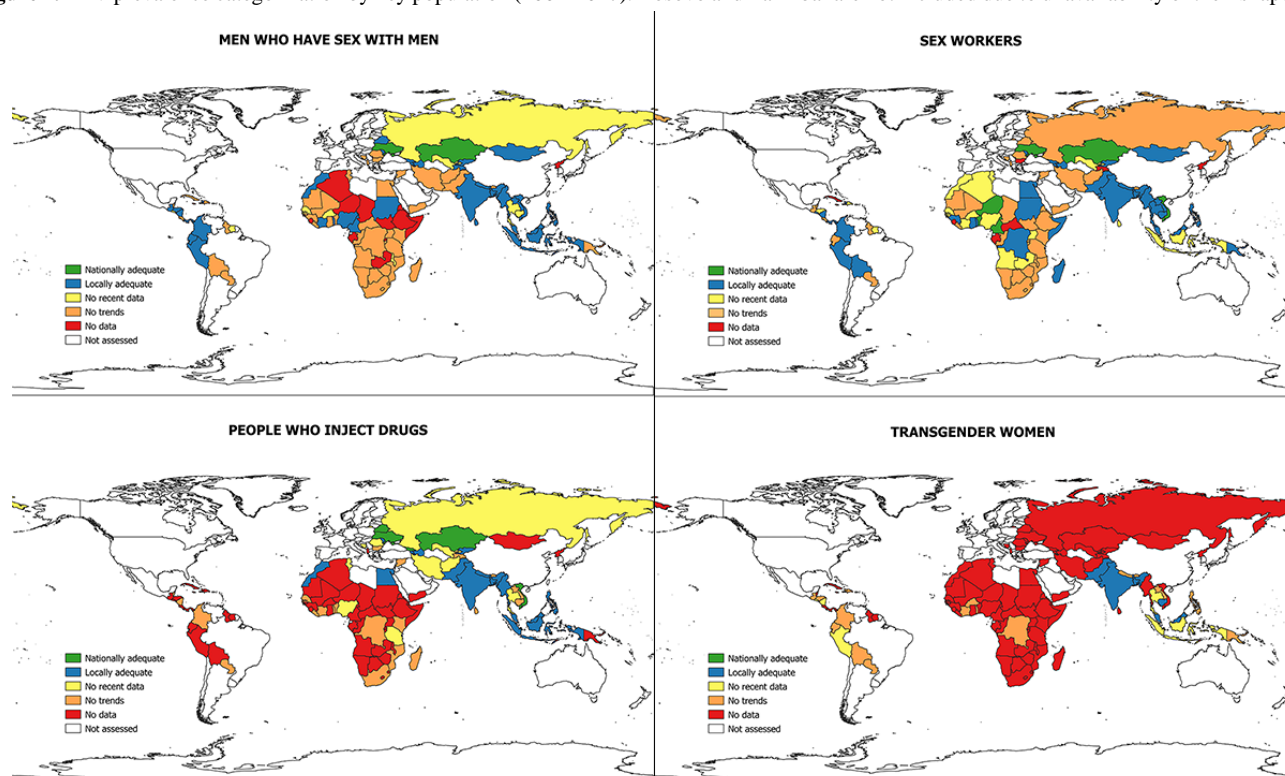
Quality was further assessed in terms of sampling methods and sample size. Sampling methods were classified as probability (eg, simple random, systematic, or stratified sampling), approximate probability (eg, RDS or TLS), and nonprobability (eg, snowball) methods. Sample size data were grouped as <100 or ≥100. For any SNU (SNU₁ or otherwise) with 3 or more data points for any KP group, the sampling methods were examined to assess whether they were consistent over time.

Maps were generated using Q-GIS (version 3.8 ; QGIS Development Team) [23]. Regional divisions for UNAIDS were used, while country-specific shapefiles were downloaded from GADM, a database of the location of the world's administrative areas.

Results

Of the 123 countries (for the full list, see [Multimedia Appendix 1](#)) assessed, 113 (91.9%) had at least 1 data point/prevalence estimate for at least 1 KP group during the period of 2001-2017. During the same period, 10 countries (Dominica, Gabon, Grenada, Democratic People's Republic of Korea, Marshall Islands, Saint Lucia, Samoa, Sao Tome and Principe, Sierra Leone, and Tuvalu) did not report any HIV prevalence data for any KP group ([Figure 2](#)).

Figure 2. HIV prevalence categorization by key population (2001-2017). Kosovo and Zanzibar are not included due to unavailability of their shapefiles.



Among the 123 countries assessed, prevalence data for HIV were available for SWs in 86.2% (106/123); MSM in 80.5% (99/123); people who inject drugs in 45.5% (56/123); and transwomen in 23.6% (29/123) of the countries. KP group-specific categorization results are presented by country in Figure 2. Approximately half of the countries assessed (63/123, 51.2%) presented data for at least 3 KPs. Very few countries (13/123, 10.6% in all; 6/123, 4.9% for SWs; 2/123, 1.6% for MSM; and 5/123, 4.1% for people who inject drugs; Table 1) were categorized as having “nationally adequate” data for any single KP. Further, while 26.8% (33/123) countries were categorized as having data that were “locally adequate” within

the selected SNUs, they were considered as “nationally inadequate”, primarily for SWs and MSM.

Of the 123 countries assessed, 78.0% (96/123) had data for at least 2 groups; and 51.2% (63/123), for at least 3 groups. Only 14.6% (18/123) had data for all 4 groups (Table 2).

Among SWs and MSM, “no trends available” was the most common category, followed by “locally adequate but nationally inadequate.” For people who inject drugs and transwomen, the most common category was “no data,” followed by “no trends” (Table 1).

Table 1. Categorization of HIV prevalence data by KP^a and region (2001-2017).

KPs	Regions						Total (N ^c =123)
	Asia and Pacific (n ^b =28)	Eastern and Southern Africa (n ^b =22)	Eastern Europe and Central Asia (n ^b =16)	Latin America (n ^b =22)	Middle East and North Africa (n ^b =11)	Western and Central Africa (n ^b =24)	
SWs^d, n (%)							
Nationally adequate	1 (3.6)	0 (0)	2 (12.5)	0 (0)	0 (0)	3 (12.5)	6 (4.9)
Locally adequate but nationally inadequate	13 (46.4)	1 (4.5)	5 (31.3)	7 (31.8)	3 (27.3)	4 (16.7)	33 (26.8)
No recent data	2 (7.1)	4 (18.2)	2 (12.5)	3 (13.6)	4 (36.4)	5 (20.8)	20 (16.3)
No trends	7 (25.0)	17 (77.3)	5 (31.3)	7 (31.8)	3 (27.3)	8 (33.3)	47 (38.2)
No data	5 (17.9)	0 (0)	2 (12.5)	5 (22.7)	1 (9.1)	4 (16.7)	17 (13.8)
MSM^e, n (%)							
Nationally adequate	0 (0)	0 (0)	2 (12.5)	0 (0)	0 (0)	0 (0)	2 (1.6)
Locally adequate but nationally inadequate	12 (42.9)	0 (0)	7 (43.8)	8 (36.4)	2 (18.2)	4 (16.7)	33 (26.8)
No recent data	2 (7.1)	1 (4.5)	3 (18.8)	2 (9.1)	0 (0)	2 (8.3)	10 (8.1)
No trends	8 (28.6)	15 (68.2)	4 (25.0)	9 (40.9)	5 (45.5)	13 (54.2)	54 (43.9)
No data	6 (21.4)	6 (27.3)	0 (0)	3 (13.6)	4 (36.4)	5 (20.8)	24 (19.5)
People who inject drugs, n (%)							
Nationally adequate	1 (3.6)	0 (0)	4 (25.0)	0 (0)	0 (0)	0 (0)	5 (4.1)
Locally adequate but nationally inadequate	8 (28.6)	0 (0)	4 (25.0)	0 (0)	2 (18.2)	0 (0)	14 (11.4)
No recent data	2 (7.1)	2 (9.1)	5 (31.3)	0 (0)	2 (18.2)	1 (4.2)	12 (9.8)
No trends	5 (17.9)	6 (27.3)	2 (12.5)	4 (18.2)	2 (18.2)	6 (25.0)	25 (20.3)
No data	12 (42.9)	14 (63.6)	1 (6.3)	18 (81.8)	5 (45.5)	17 (70.8)	67 (54.5)
Transwomen, n (%)							
Nationally adequate	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
Locally adequate but nationally inadequate	5 (17.9)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	5 (4.1)
No recent data	2 (7.1)	0 (0)	0 (0)	3 (13.6)	0 (0)	0 (0)	5 (4.1)
No trends	6 (21.4)	1 (4.5)	0 (0)	8 (36.4)	0 (0)	4 (16.7)	19 (15.4)
No data	15 (53.6)	21 (95.5)	16 (100.0)	11 (50.0)	11 (100.0)	20 (83.3)	94 (76.4)

^aKP: key population.^bNumber of countries in a region.^cTotal number of countries assessed.^dSWs: sex workers.^eMSM: men who have sex with men.

Table 2. Number and proportion of countries distributed by number of KPs^a with HIV prevalence SNU^b data (2001-2017; N=123).

Status of HIV prevalence SNU data	Number of countries, n (%)
No data	10 (8.1)
1 population	17 (13.8)
2 populations	33 (26.8)
3 populations	45 (36.6)
4 populations	18 (14.6)

^aKP: key population.

^bSNU: subnational unit.

Different patterns of availability and quality were evident among the regions. Considering the top 2 categories, namely “nationally adequate” and “locally adequate,” on average, availability and quality of data for SWs were better in the Asia and Pacific region than in other regions. Better data availability and quality were observed for MSM in the Asia and Pacific and Eastern Europe and Central Asia regions. While data for people who inject drugs were available for countries in the Eastern Europe and Central Asia regions, the majority were categorized as “no recent data.” Most countries in the other regions were categorized under “no data” for people who inject drugs.

[Multimedia Appendix 2](#) presents the number of HIV prevalence data points available by KPs over time as well as the availability of sample size information and number of data points with a sample size >100. From 2001 to 2017, the number of data points increased with fluctuations for MSM and transwomen, fluctuated but stabilized for people who inject drugs, and fluctuated but decreased for SWs. Information on sample size was available for more than 80% of the HIV prevalence data points for MSM (1217/1456, 83.6%) and transwomen (226/273, 82.8%), and for more than 50% of the HIV prevalence data points for SWs (2470/4368, 56.5%) and people who inject drugs (1194/2211, 54.0%). Among those data points with reported sample sizes, 83.9% (1002/1194) reported a sample size >100 for people who

inject drugs; and 82.3% (1002/1217), for MSM. An overall increase in the number and proportions of data points with sample sizes >100 was observed, especially for MSM, people who inject drugs, and transwomen.

[Table 3](#) presents the sampling methods used for surveys or sentinel surveillance in those SNUs with at least 3 data points for any KP (n=68). Of the total SNUs, 9.5% (416/4368), 19.2% (280/1456), 11.3% (249/2211), and 20.9% (57/273) met the criteria of 3 data points per KP for SWs, MSM, people who inject drugs, and transwomen. Overall, a small proportion of SNUs, namely 18.3% (76/416) for SWs, 10.7% (30/280) for MSM, 10.4% (26/249) for people who inject drugs, and 24.6% (14/57) for transwomen, used probability sampling or approximate probability sampling. Snowball sampling was the most common nonprobability sampling method across all KP groups. Moreover, 46.6% (194/416) of those SNUs reporting at least 3 data points for SWs did not report any sampling methods. Cluster, systematic, simple random, or stratified sampling methods were mostly applied from 2001 to 2008 and in a few countries where venue- or site-based sentinel surveillance had been implemented (data not shown). The comparable proportions for the other KPs are as follows: 35.4% (99/280) for MSM, 39.8% (99/249) for people who inject drugs, and 29.8% (17/57) for transwomen ([Table 3](#)).

Table 3. Sampling methods used for surveys in SNU^a with at least 3 data points for any KP^b (N^c=68).

Sampling methods	KPs			
	SWs ^d (N ^e =416)	MSM ^f (N ^e =280)	People who inject drugs (N ^e =249)	Transwomen (N ^e =57)
Nonprobability sampling, n (%)				
Cluster	34 (8.2)	10 (3.6)	17 (6.8)	5 (8.8)
Convenience	32 (7.7)	18 (6.4)	10 (4.0)	2 (3.5)
Facility-based	15 (3.6)	13 (4.6)	15 (6.0)	6 (10.5)
Snowball	62 (14.9)	99 (35.4)	74 (29.7)	13 (22.8)
Other nonprobability sampling	3 (0.7)	11 (3.9)	8 (3.2)	0 (0)
Probability sampling, n (%)				
Proportionate to population size	12 (2.9)	5 (1.8)	3 (1.2)	2 (3.5)
Respondent-driven sampling	9 (2.2)	4 (1.4)	4 (1.6)	3 (5.3)
Systematic, simple random, or stratified	41 (9.9)	14 (5.0)	12 (4.8)	7 (12.3)
Time-location sampling	14 (3.4)	7 (2.5)	7 (2.8)	2 (3.5)
Unknown, n (%)	194 (46.6)	99 (35.4)	99 (39.8)	17 (29.8)

^aSNU: Subnational unit.

^bKP: key population.

^cTotal number of countries.

^dSWs: sex workers.

^eTotal number of SNU with at least 3 data points.

^fMSM: men who have sex with men.

We also examined the sampling methods used at the country level. In terms of KPs, the results showed that 47.2% (58/123), 36.6% (45/123), 25.2% (31/123), and 8.1% (10/123) of the countries reported sampling methods for at least 3 data points for MSM, SWs, people who inject drugs, and transwomen, respectively. Among these groups of countries, 12.2% (15/123), 12.2% (15/123), 6.5% (8/123), and 1.6% (2/123) of the countries used approximate probability sampling methods consistently for MSM, SWs, people who inject drugs, and transwomen, respectively (data not shown).

Of the 106 countries that presented any subnational HIV prevalence data among SWs, 14.2% (15/106; Bangladesh, Nepal, Pakistan, Papua New Guinea, Philippines, Thailand, Paraguay, Peru, Guyana, Suriname, Egypt, Bolivia, Guatemala, Paraguay, and Côte d'Ivoire) had disaggregated data for male SWs. Of the 56 countries that presented any prevalence data for people who inject drugs, 16.1% (9/56) (Bangladesh, Nepal, Philippines, Kenya, United Republic of Tanzania, Republic of Moldova, Russia, Egypt, and Iran) had disaggregated data for female injectors. Moreover, 26.8% (33/123) of countries (Belize, Bangladesh, Bhutan, Bolivia, Cambodia, Columbia, Costa Rica, Cote d'Ivoire, Dominica Republic, Democratic Republic of Congo, Ecuador, El Salvador, Fiji, Guatemala, Guyana, Haiti, Honduras, India, Indonesia, Laos, Malaysia, Nepal, Nicaragua, Panama, Paraguay, Peru, Philippines, Papua New Guinea, Samoa, Thailand, Tuvalu, Uruguay, and Vanuatu) clearly listed transwomen as the target population for the survey at least once;

note that transwomen may have been included in the surveys on MSM in other countries.

Discussion

Despite general improvements in the availability and quality of HIV prevalence estimates among KPs in low-and middle-income countries from 2001 to 2017, both remain woefully inadequate compared with HIV surveillance data from general populations (ie, antenatal care (ANC) sentinel surveillance and population-based estimates of HIV prevalence). These essential epidemiologic data are critical for monitoring the HIV epidemic and response regardless of epidemic type. Very few assessed countries (13/123, 10.6%) were categorized as having “nationally adequate” data for any single KP. Only 26.8% (33/123) of countries assessed were categorized as having data that were “locally adequate within selected SNU but nationally inadequate,” primarily for SWs and MSM. In total, only 37.4% (46/123) of countries assessed had at least locally adequate data for local program planning and monitoring. Lack of nationally representative data presents a great challenge for strategic planning, advocacy, and target setting, as well as cascade analyses, which allow programs to identify and target differential access, coverage, and quality of services. Countries may misuse subnational data from a small proportion of the population to represent the entire country without appropriate adjustment. Such misuse of data can lead to incorrect resource allocation and overall estimation of HIV burden. Models, such as those used in the Spectrum suite (Avenir Health), provide one

approach to extrapolate data, though input data quality must still be adequate.

Global, regional and national HIV prevalence trends are published by UNAIDS annually. However, tracking the trends of HIV prevalence among KPs remains a major challenge. Even till 2017, 36 years into the HIV epidemic, many programs still could not assess whether the programmatic responses among KP communities were improving or regressing. In Africa, where the HIV epidemic is more generalized, epidemics among the KPs were mostly neglected until very recently, when these countries started to gain epidemic control in the general population. About half (59/123, 48.0%) and one-third (46/123, 37.4%) of countries assessed presented at least 3 data points for SWs and MSM, respectively, from 2001 to 2017, despite the technical guidance urging the collection of such data every 2-3 years [10,24,25]. This challenge is the greatest in Eastern Europe and Central Asia for all 4 groups, followed by Latin America and the Caribbean, and the West and Central Africa regions.

Statistically representative estimates require the use of a probability sampling method and an adequate sample size. The use of approximate probability sampling methods has increased since 2003, especially in the last 5 years for MSM and SWs (data not shown). However, consistent use of such sampling methods remains limited. Inadequate sample sizes remain an issue despite an increasing trend in the number of estimates (among MSM, people who inject drugs, and transwomen) and surveys reporting sample size information (among SWs and people who inject drugs) (Multimedia Appendix 2).

Collecting information on the HIV epidemic among KPs continues to be uniquely challenging. While HIV surveillance approaches within generalized epidemics continue to shift toward reliance on routine ANC programmatic testing data, KP programmatic data face several important hurdles. The first hurdle concerns KP group disaggregation. In order to be able to disaggregate HIV testing data by KP groups, it would be necessary to collect and report information on these groups. The second issue concerns coverage and representativeness; whereas high majorities of pregnant women attend first ANC visits, HIV testing service coverage among KPs is more variable and difficult to define. Service providers need to be properly sensitized and trained for risk ascertainment and documentation. However, any activities that could potentially unmask people who engage in stigmatized or illegal behaviors should be avoided, or at least carefully balanced against the rights and safety of community members, who should be closely involved with related policy and technical decisions. Such efforts should continue to ensure that essential health data are also collected directly from within the communities, including through community-led monitoring, and settings that provide prevention, care, and treatment services to these populations. Such approaches will enable evolution toward more integrated and sustainable approaches, ensuring strategic information in the long term.

Health information systems must be strengthened to enable collection of person-centered individual-level longitudinal information about KPs. This strengthening should include investments in robust data security and confidentiality

procedures. It is important to establish shared ownership and integration of health information systems between government institutions and nongovernmental organizations (NGOs), with involvement of communities and civil society playing an essential part. As a first step, systems that collect prevention and HIV testing data for KPs (usually owned by NGOs, at physical or virtual locations) should be linked with systems that collect treatment data (typically owned by governmental institutions). Using common unique identification standards, the entire prevention, testing, treatment, and viral load cascades can be measured for the populations served at any given point in time. Again, it is important to emphasize that data security concerns may prevent NGOs from sharing individual-level data [26], and this aspect must be adequately addressed to alleviate community concerns. Some examples indicate how HIV-related data among KPs are gathered from all service providers in a single information system [8]. Such an arrangement will ensure that programmatic and real-time data can be used for monitoring the epidemic among KPs. While external donors shall continue financing such data systems and building in-country capacity, national stakeholders need to increase financing for government institutions and NGOs for long-term, localized solutions for collection and use of quality data.

There are several limitations to this analysis. This analysis did not include data collected from prisoners and some other affected populations defined in the WHO guidelines [2]. Despite the efforts to collect and review all survey data from available sources, some data were not accessible. Many accessed survey reports were draft versions, and final reports may present different results (eg, after weighted analysis is conducted). Many reports did not describe basic survey elements such as representativeness, sample size, sampling methods, and eligibility criteria. Lack of such basic elements limited the establishment of consistent quality metrics or a composite scoring system. The categorization, a preliminary attempt to assess data availability and quality in combination, did not factor the consistency in sampling methods across years. Nor was the comparability of data across countries over time assessed. HIV prevalence is less sensitive than HIV incidence or mortality in gauging the impact of the HIV response. As incidence and viral suppression data become available, this categorization approach may be useful to understand the monitoring quality of these critical indicators. Moreover, trend analysis requires a minimum of 3 data points at the same SNU, with consistent application of probability sampling or approximate probability sampling methods. This definition yielded few SNUs for trend analysis, as the majority of the SNUs applied only nonprobability sampling methods. Last, the sample size selection of 100 as the threshold was arbitrary. Sample size considerations of each individual survey could not be reviewed for many of the available data.

Notwithstanding a slight decline in the availability of HIV prevalence data among SWs from 2001 to 2017, availability of data from the other reviewed populations increased during the same period. This increase is partly attributable to increased global financial investments and technical advances in implementing surveys among difficult-to-survey populations. Overall, however, the continued inadequacy of the most essential

data is concerning. Regardless of the epidemic settings, basic epidemiologic data are essential for monitoring HIV responses and understanding progress toward the 95-95-95 goals. Ultimately, the success of the HIV response will hinge on our

ability to ensure service coverage and quality in the last mile toward ending HIV as a public health threat by 2030. The global goal of ending HIV as an epidemic cannot be achieved without controlling the epidemic among KPs.

Acknowledgments

The authors would like to thank the Joint United Nations Programme on HIV/AIDS (UNAIDS), the World Health Organization (WHO) regional and country strategic information advisors, and the Global Fund public health and monitoring evaluation specialists for providing and reviewing some of the data elements. Special thanks are due to Yaou Sheng and Meiwen Zhang for mapping the relevant studies up to December 2016.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Country names.

[DOCX File, 14 KB - [publichealth_v6i4e21688_app1.docx](#)]

Multimedia Appendix 2

Overall number of data points.

[DOCX File, 20 KB - [publichealth_v6i4e21688_app2.docx](#)]

References

1. UNAIDS. Global AIDS Update 2020, Seizing the moment: Tackling entrenched inequalities to end epidemics. Geneva: UNAIDS; 2020 Jul 06. URL: https://www.unaids.org/sites/default/files/media_asset/2020_global-aids-report_en.pdf [accessed 2020-09-25]
2. World Health Organization. Consolidated Guidelines on HIV Prevention, Diagnosis, Treatment and Care for Key Populations Update. Geneva: World Health Organization; 2016 Jul 01. URL: <https://apps.who.int/iris/bitstream/handle/10665/246200/9789241511124-eng.pdf?sequence=8> [accessed 2020-09-25]
3. Baral SD. The epidemiology and vulnerability of missing and indigenous populations. The epidemiology and vulnerability of missing and indigenous populations. Amsterdam, the Netherlands: International AIDS Conference; 2018 Jul 22. URL: <http://programme.aids2018.org/People/PeopleDetailStandalone/57> [accessed 2020-09-25]
4. Liu C, Fu R, Tang W, Cao B, Pan S, Wei C, et al. Transplantation or rurality? Migration and HIV risk among Chinese men who have sex with men in the urban areas. *J Int AIDS Soc* 2018 Jan;21(1):e25039 [FREE Full text] [doi: [10.1002/jia2.25039](https://doi.org/10.1002/jia2.25039)] [Medline: [29327442](https://pubmed.ncbi.nlm.nih.gov/29327442/)]
5. Udoh I, Mantell JE, Sandfort T, Eighmy MA. Potential pathways to HIV/AIDS transmission in the Niger Delta of Nigeria: poverty, migration and commercial sex. *AIDS Care* 2009 May;21(5):567-574 [FREE Full text] [doi: [10.1080/09540120802301840](https://doi.org/10.1080/09540120802301840)] [Medline: [19444664](https://pubmed.ncbi.nlm.nih.gov/19444664/)]
6. Shannon K, Crago A, Baral SD, Bekker L, Kerrigan D, Decker MR, et al. The global response and unmet actions for HIV and sex workers. *Lancet* 2018 Aug 25;392(10148):698-710 [FREE Full text] [doi: [10.1016/S0140-6736\(18\)31439-9](https://doi.org/10.1016/S0140-6736(18)31439-9)] [Medline: [30037733](https://pubmed.ncbi.nlm.nih.gov/30037733/)]
7. Davis SL, Goedel WC, Emerson J, Guven BS. Punitive laws, key population size estimates, and Global AIDS Response Progress Reports: An ecological study of 154 countries. *J Int AIDS Soc* 2017 Mar 17;20(1):21386 [FREE Full text] [doi: [10.7448/IAS.20.1.21386](https://doi.org/10.7448/IAS.20.1.21386)] [Medline: [28364567](https://pubmed.ncbi.nlm.nih.gov/28364567/)]
8. Burrows D, McCallum L, Parsons D, Falkenberg H. Global Summary of Findings of an Assessment of HIV Service Packages for Key Populations in Six Regions. Washington, DC: APMG Health; 2019 Apr. URL: <https://apmghealth.com/project/assessment-existence-and-use-hiv-packages-services-key-populations> [accessed 2020-09-25]
9. Diaz T, Garcia-Calleja JM, Ghys PD, Sabin K. Advances and future directions in HIV surveillance in low- and middle-income countries. *Curr Opin HIV AIDS* 2009 Jul;4(4):253-259. [doi: [10.1097/COH.0b013e32832c1898](https://doi.org/10.1097/COH.0b013e32832c1898)] [Medline: [19532061](https://pubmed.ncbi.nlm.nih.gov/19532061/)]
10. UNAIDS, fhi360, WHO, CDC, PEPFAR. Biobehavioral survey guidelines for populations at Risk for HIV. www.who.int. Geneva: World Health Organization; 2017. URL: <http://www.who.int/hiv/pub/guidelines/biobehavioral-hiv-survey/en/> [accessed 2020-09-25]
11. Magnani R, Sabin K, Saidel T, Heckathorn D. Review of sampling hard-to-reach and hidden populations for HIV surveillance. *AIDS* 2005 May;19 Suppl 2(Supplement 2):S67-S72 [FREE Full text] [doi: [10.1097/01.aids.0000172879.20628.e1](https://doi.org/10.1097/01.aids.0000172879.20628.e1)] [Medline: [15930843](https://pubmed.ncbi.nlm.nih.gov/15930843/)]

12. Miller WM, Buckingham L, Sánchez-Domínguez MS, Morales-Miranda S, Paz-Bailey G. Systematic review of HIV prevalence studies among key populations in Latin America and the Caribbean. *Salud Publica Mex* 2013 Jul 03;55 Suppl 1:S65-S78. [doi: [10.21149/spm.v55s1.5099](https://doi.org/10.21149/spm.v55s1.5099)] [Medline: [23918059](https://pubmed.ncbi.nlm.nih.gov/23918059/)]
13. Mumtaz GR, Weiss HA, Thomas SL, Riome S, Setayesh H, Riedner G, et al. HIV among people who inject drugs in the Middle East and North Africa: systematic review and data synthesis. *PLoS Med* 2014 Jun 17;11(6):e1001663 [FREE Full text] [doi: [10.1371/journal.pmed.1001663](https://doi.org/10.1371/journal.pmed.1001663)] [Medline: [24937136](https://pubmed.ncbi.nlm.nih.gov/24937136/)]
14. Chersich MF, Luchters S, Ntaganira I, Gerbase A, Lo Y, Scorgie F, et al. Priority interventions to reduce HIV transmission in sex work settings in sub-Saharan Africa and delivery of these services. *J Int AIDS Soc* 2013 Mar 04;16:17980 [FREE Full text] [doi: [10.7448/IAS.16.1.17980](https://doi.org/10.7448/IAS.16.1.17980)] [Medline: [23462140](https://pubmed.ncbi.nlm.nih.gov/23462140/)]
15. Muraguri N, Temmerman M, Geibel S. A decade of research involving men who have sex with men in sub-Saharan Africa: current knowledge and future directions. *Sahara J* 2012;9(3):137-147. [doi: [10.1080/17290376.2012.744176](https://doi.org/10.1080/17290376.2012.744176)] [Medline: [23237068](https://pubmed.ncbi.nlm.nih.gov/23237068/)]
16. Mumtaz G, Hilmi N, McFarland W, Kaplan RL, Akala FA, Semini I, et al. Are HIV epidemics among men who have sex with men emerging in the Middle East and North Africa? A systematic review and data synthesis. *PLoS Med* 2010 Aug 2;8(8):e1000444 [FREE Full text] [doi: [10.1371/journal.pmed.1000444](https://doi.org/10.1371/journal.pmed.1000444)] [Medline: [21829329](https://pubmed.ncbi.nlm.nih.gov/21829329/)]
17. Aceijas C, Stimson GV, Hickman M, Rhodes T, United Nations Reference Group on HIV/AIDS Prevention and Care among IDU in Developing/Transitional Countries. Global overview of injecting drug use and HIV infection among injecting drug users. *AIDS* 2004 Nov 19;18(17):2295-2303. [doi: [10.1097/00002030-200411190-00010](https://doi.org/10.1097/00002030-200411190-00010)] [Medline: [15577542](https://pubmed.ncbi.nlm.nih.gov/15577542/)]
18. Bozicevic I, Voncina L, Zigrovic L, Munz M, Lazarus JV. HIV epidemics among men who have sex with men in central and eastern Europe. *Sex Transm Infect* 2009 Sep 22;85(5):336-342. [doi: [10.1136/sti.2008.035436](https://doi.org/10.1136/sti.2008.035436)] [Medline: [19773456](https://pubmed.ncbi.nlm.nih.gov/19773456/)]
19. Sabin K, Zhao J, Garcia Calleja JM, Sheng Y, Arias Garcia S, Reinisch A, et al. Availability and quality of size estimations of female sex workers, men who have sex with men, people who inject drugs and transgender women in low- and middle-income countries. *PLoS One* 2016 May 10;11(5):e0155150 [FREE Full text] [doi: [10.1371/journal.pone.0155150](https://doi.org/10.1371/journal.pone.0155150)] [Medline: [27163256](https://pubmed.ncbi.nlm.nih.gov/27163256/)]
20. UNAIDS, UNICEF, WHO, ADB. HIV and AIDS Data Hub For Asia Pacific, Evidence to Action. Bangkok, Thailand: UNAIDS URL: <https://www.aidsdatahub.org/> [accessed 2020-09-25]
21. The Global Fund. Funding Model: Eligibility. Geneva, Switzerland: The Global Fund; 2014. URL: <https://www.theglobalfund.org/en/funding-model/before-applying/eligibility/> [accessed 2020-09-25]
22. Central Intelligence Agency. The World Factbook. Washington, DC: Central Intelligence Agency URL: <https://www.cia.gov/library/publications/the-world-factbook/> [accessed 2020-09-25]
23. QGIS. QGIS: A Free and Open Source Geographic Information System. URL: <http://www.qgis.org/en/site/> [accessed 2020-09-25]
24. UNAIDS/WHO Working Group on Global HIV/AIDS and STI Surveillance. Guidelines on Estimating the Size of Populations Most at Risk to HIV. Geneva, Switzerland: WHO and UNAIDS; 2011. URL: https://data.unaids.org/pub/manual/2010/guidelines_popnestimationsize_en.pdf [accessed 2020-09-25]
25. UNAIDS. Summary of indicators for global AIDS monitoring. In: *Global AIDS Monitoring 2019: Indicators for Monitoring the 2016 Political Declaration on Ending AIDS*. Geneva, Switzerland: UNAIDS; 2016:5-8.
26. Heidel A, Hagist C. Potential benefits and risks resulting from the introduction of health apps and wearables into the German statutory health care system: Scoping review. *JMIR Mhealth Uhealth* 2020 Sep 23;8(9):e16444 [FREE Full text] [doi: [10.2196/16444](https://doi.org/10.2196/16444)] [Medline: [32965231](https://pubmed.ncbi.nlm.nih.gov/32965231/)]

Abbreviations

- ANC:** antenatal care
- BBS:** bio-behavioral surveys
- FSW:** female sex worker
- IDU:** injecting drug use
- KP:** key population
- MSM:** men who have sex with men
- NGO:** nongovernmental organizations
- PWID:** people who inject drugs
- RDS:** respondent-driven sampling
- SNU:** subnational unit
- SW:** sex worker
- TG:** transgender
- TLS:** time-location sampling
- UNAIDS:** United Nations Programme on HIV/AIDS
- WHO:** World Health Organization

Edited by T Sanchez; submitted 22.06.20; peer-reviewed by W Hladik, J Neal; comments to author 06.08.20; revised version received 01.10.20; accepted 20.10.20; published 17.11.20.

Please cite as:

Arias Garcia S, Chen J, Calleja JG, Sabin K, Ogbuanu C, Lowrance D, Zhao J

Availability and Quality of Surveillance and Survey Data on HIV Prevalence Among Sex Workers, Men Who Have Sex With Men, People Who Inject Drugs, and Transgender Women in Low- and Middle-Income Countries: Review of Available Data (2001-2017)

JMIR Public Health Surveill 2020;6(4):e21688

URL: <http://publichealth.jmir.org/2020/4/e21688/>

doi: [10.2196/21688](https://doi.org/10.2196/21688)

PMID: [33200996](https://pubmed.ncbi.nlm.nih.gov/33200996/)

©Sonia Arias Garcia, Jia Chen, Jesus Garcia Calleja, Keith Sabin, Chinelo Ogbuanu, David Lowrance, Jinkou Zhao. Originally published in JMIR Public Health and Surveillance (<http://publichealth.jmir.org>), 17.11.2020. This is an open-access article distributed under the terms of the Creative Commons Attribution License (<https://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in JMIR Public Health and Surveillance, is properly cited. The complete bibliographic information, a link to the original publication on <http://publichealth.jmir.org>, as well as this copyright and license information must be included.

Original Paper

YouTube Video Comments on Healthy Eating: Descriptive and Predictive Analysis

Shasha Teng¹, PhD; Kok Wei Khong¹, PhD; Saeed Pahlevan Sharif¹, PhD; Amr Ahmed², PhD

¹Faculty of Business and Law, Taylor's University, Subang Jaya, Malaysia

²School of Computer Science, University of Nottingham Malaysia Campus, Semenyih, Selangor, Malaysia

Corresponding Author:

Shasha Teng, PhD

Faculty of Business and Law

Taylor's University

Lakeside Campus, 1 Jalan Taylor's

Subang Jaya,

Malaysia

Phone: 60 3 5629 56666

Email: shatengsha@gmail.com

Abstract

Background: Poor nutrition and food selection lead to health issues such as obesity, cardiovascular disease, diabetes, and cancer. This study of YouTube comments aims to uncover patterns of food choices and the factors driving them, in addition to exploring the sentiments of healthy eating in networked communities.

Objective: The objectives of the study are to explore the determinants, motives, and barriers to healthy eating behaviors in online communities and provide insight into YouTube video commenters' perceptions and sentiments of healthy eating through text mining techniques.

Methods: This paper applied text mining techniques to identify and categorize meaningful healthy eating determinants. These determinants were then incorporated into hypothetically defined constructs that reflect their thematic and sentimental nature in order to test our proposed model using a variance-based structural equation modeling procedure.

Results: With a dataset of 4654 comments extracted from YouTube videos in the context of Malaysia, we apply a text mining method to analyze the perceptions and behavior of healthy eating. There were 10 clusters identified with regard to food ingredients, food price, food choice, food portion, well-being, cooking, and culture in the concept of healthy eating. The structural equation modeling results show that clusters are positively associated with healthy eating with all *P* values less than .001, indicating a statistical significance of the study results. People hold complex and multifaceted beliefs about healthy eating in the context of YouTube videos. Fruits and vegetables are the epitome of healthy foods. Despite having a favorable perception of healthy eating, people may not purchase commonly recognized healthy food if it has a premium price. People associate healthy eating with weight concerns. Food taste, variety, and availability are identified as reasons why Malaysians cannot act on eating healthily.

Conclusions: This study offers significant value to the existing literature of health-related studies by investigating the rich and diverse social media data gleaned from YouTube. This research integrated text mining analytics with predictive modeling techniques to identify thematic constructs and analyze the sentiments of healthy eating.

(*JMIR Public Health Surveill* 2020;6(4):e19618) doi:[10.2196/19618](https://doi.org/10.2196/19618)

KEYWORDS

YouTube comments; text mining; healthy eating; clustering; structural equation modeling

Introduction

Background

Poor nutrition and food selection lead to health issues such as obesity, cardiovascular disease, diabetes, and cancer. In order to reduce the risk of these diseases, it is important to follow

healthy nutrition choices. Food selection plays a major role in a healthy lifestyle. Studies have shown that taste, cost, nutrition, convenience, pleasure, and weight control are the predicting factors for food selection [1]. This aligns with a number of dietary recommendations and public health campaigns aiming to encourage people to eat healthily.

The majority of online comments contain opinions. Social media platforms serve as a key source for obtaining large, current datasets [2]. This study focuses on YouTube comments because YouTube's environment is multilingual, multidomain, and multicultural [2], and YouTube audiences, in turn, are international and intergenerational. In other words, the diverse nature of YouTube comments makes it a potentially valuable source of opinions on videos and the issues depicted in them [3]. In studies on health-related issues, YouTube qualifies itself as a natural candidate for researchers to study topics in the development of community and data exchange [4]. YouTube contains a large volume of comments made by video audiences. Although these comments reflect the commenters' assumptions about food choices and health awareness [5], little is known about what people are discussing in terms of healthy eating. The aim of this study of YouTube video comments related to healthy eating is to uncover the reasons for and patterns of food choices in networked communities.

Objectives

The objectives of the study are to explore the determinants, motives, and barriers to healthy eating behaviors in online communities and provide insight into YouTube video commenters' perceptions and sentiments of healthy eating through text mining techniques. The study addresses the following questions: Can we identify the relevant topics and categories of healthy eating comments meaningfully? Can we interpret people's sentiments related to healthy eating?

Review on Healthy Eating

Healthy eating is defined as having a diet that is low in fat and high in fiber, with more fruits and vegetables in addition to balance and variety [6]. Bisogni and colleagues [7] conducted a systematic review of past qualitative research studies to understand how people interpreted healthy eating. Their research revealed that people associated healthy eating with fruits and vegetables, animal-based products, safe food, functional food, general nutrients, fiber, vitamins and minerals, balance, variety, and moderation, with descriptors such as fat, natural, organic, homemade, and so on. People discussed healthy eating in terms of foods, nutrients, or other components. Another study focused on group interviews with adolescents from high school. The results showed that young people considered healthy eating to be eating the right types of food, and they went ahead to name specific foods, such as fruit, salad, and yogurt [6]. They also included carbohydrate-rich foods (eg, rice and pasta), lean meat (baked chicken in particular), and tofu. Home-grown vegetables, greens, corn, and celery were mentioned during the interviews. The adolescents shared their understanding of unhealthy eating by naming specific foods, such as fast food, candy, soda pop, and chips [6]. Lu and Gursoy [8] examined the influencing factor of organic food on consumer decision making. The results indicated that healthy food described not only a low-fat or low-calorie diet but also a meal loaded with nutrients and quality ingredients (eg, organic food).

In the 20th century, the Mediterranean diet pyramid was presented in the study by Willett and colleagues [9]. This diet is characterized by abundant plant food, fresh fruits daily, olive oil as the principal source of fat, dairy products (in particular

cheese and yogurt), fish and poultry consumed in moderate amounts and red meat consumed in low amounts, and wine consumed in low or moderate amounts during meals [9]. The study exemplified the abundance of plant food with couscous, vegetables, and legumes in North Africa, pasta, rice, and vegetables in South Europe, and bulgur, rice and vegetables, chickpeas, and other beans in the Eastern Mediterranean regions. Olive oil is low in saturated fat, and it is a major source of fat in the Mediterranean diet. Dairy products are included in this diet from animals such as goats, sheep, cows, and buffalo. These products are consumed in small to moderate portions. Compared with the high intake of meat in the Western diet, the Mediterranean diet recommends red meat in low amounts, along with moderate consumption of fish and eggs. A healthy lifestyle would require regular physical activity and sufficient relaxation. Carefully prepared delicious food and sharing food with family and friends stimulated the enjoyment of a healthy Mediterranean diet. Apart from academic research, the public health sector in the United States promoted healthy eating by releasing the Healthy Eating Index (HEI) in 1995. The HEI-2005 dietary guidelines advise people to eat fruit instead of fruit juice, to eat dark green and orange vegetables, and to eat legumes. Milk, meat, and beans are included in the index. HEI-2005 assesses the intake of food and nutrients from a density basis, which is calculated as a ratio to energy intake. The 1200- to 2400-calorie weekly pattern meets the recommended nutrient intake, including a 1000-calorie weekly intake of dark green and orange vegetables and legumes. HEI-2005 includes guidance on sodium and saturated fat intake as well. The dietary guidelines encourage people to consume low-fat food free of added sugar and avoid solid fat and alcoholic beverages [10].

Many studies have explored the determinants of healthy eating behavior. In terms of food characteristics, Lu and Gursoy [8] examined food quality from the diners' decision-making aspect. The results showed that food presentation, the presence of nutritious ingredients, taste, and freshness are the critical factors that influence the diners' attitudes toward visiting certain restaurants. Examining a review of academic papers focused on children and youths, Taylor et al [11] revealed that children's food preferences are an important predictor of healthy eating. They believe that a lack of nutrient knowledge can lead to poor food choices [11]. Differences in the determinants of eating behaviors were found in boys and girls. Deshpande et al [1] investigated factors influencing college students' healthy eating habits and found that female students tend to eat more fatty food than male students. They also concluded that female and male students are motivated to eat a healthy diet by different factors. This result is consistent with the study by Croll et al [6]. Girls eat healthy food in order to have a better appearance, whereas boys eat healthily to maintain energy. Food price is considered to be an economic determinant of healthy eating. As agreed by Taylor and colleagues [11], the most common consideration in reference to food choice is food price. In other words, having a low income leads to selecting food that is high in sugar and fat as these foods are cheaper. This also means that people have low-quality meals [8]. Moreover, another study found that the food price is higher for healthy food than any other food in grocery stores. These grocery stores appear to have more positive reviews regarding the availability of quality healthy

food [12]. Parenting styles and one's peers are regarded as the social determinants of healthy eating. Students off campus choose different foods from students living on campus [1]. The physical environment determinants include food portion size and school environment. Studies have been carried out to implement environmental interventions in reference to healthy eating [1,13]. This provides a chance to eliminate or weaken an unhealthy environment so it is easier for people to engage in health-enhancing behavior. In addition, environmental interventions promote role models and social support for the members of the community.

Studies have investigated motives influencing healthy eating behavior as well and have indicated that a healthy appearance, positive feelings, and preventing disease are the factors behind college students having a healthy diet [1]. Similar findings were included in a study by Shepherd et al [14]. Previous work revealed that weight management is influenced by healthy eating [15]. A number of barriers to healthy eating were examined as well. Shepherd et al [14] identified that the poor availability of healthy food at school, a lack of healthy eating information from teachers and friends, the students' preferences for fast food, and expensive healthy food are barrier factors [14]. Deshpande et al [1] included time sufficiency, convenience, and a higher perception of stress and low self-esteem as student barriers to healthy eating. It is widely known that a lack of nutrition knowledge is attributed to barriers to healthy eating.

YouTube Video Comments

We reviewed the literature related to YouTube video comments and found that a number of studies have categorized YouTube comments through various approaches given the complexity of YouTube comment characteristics. Madden et al [16] applied a classification scheme that covers impressions, advice, opinions, and comments in terms of YouTube use. This scheme reveals differences in YouTube video commenting behavior regarding different genres. Their study clustered 10 detailed categories of YouTube comments, including information, advice, impression, opinion, responses from previous comments, expression of personal feelings, general conversation, site process, video content description, and nonresponse messages [16]. Another study categorized YouTube comments related to health issues into different groups: self-disclosure comments, feedback for the video uploader, factual in nature, help-related messages, and so on [17]. Wendt et al [18] studied significant differences in user perceptions of viral stealth videos and product advertising videos. Topic, pragmatics, and sentiment are the three main categories of YouTube videos. It is recognized that comments are generally positive toward these videos. Madden et al [16] explored the nature of YouTube comments to understand perceptions of the utility of YouTube videos by developing a category scheme. Their scheme included questions, responses, feedback (general), feedback (positive/agree), feedback (negative/disagree), appreciation/acknowledgment, giving personal information/situation, personal action, spam/promotion, and unclassifiable messages [19]. Besides categorizing YouTube comments, several studies explored the characteristics of YouTube videos, such as video type, viewer engagement level, technique use level, and message level [20]. Ferchaud et al [21] established categories from video content

feature and production feature aspects in order to explore parasocial attributes and YouTube personalities [21]. Zhang et al [22] demonstrated that statistical evidence, narrative, humor, fear image, and peer influence are important types of video message appeal that stimulate more views, likes, and comments on YouTube videos related to healthy eating.

Text Analytics

In studies of health research, surveys and consultations with patients have the advantage of involving a large sample. Conducting these surveys may potentially prevent geographical dependence, yet the number of answers is restricted in questionnaires, which can reduce the chances of capturing deep input [23]. Additionally, low response rates and the difficulty of obtaining an essential understanding of sensitive issues are other disadvantages of traditional survey methods [24]. In contrast, interviews and focus groups can offer the possibility of obtaining detailed information [23]. However, given the relatively small sample size, these methods may overlook important aspects of the interviewees' opinions. Long and diffused answers generated from interviews make them difficult to understand or analyze through a traditional approach [25]. Bicquelet [23] applied the text mining technique to gather online data in order to understand patient needs. This increasingly popular social research technique has been adapted to analyze levels of interest in a topic or a time series analysis of trends in interest [3]. Text mining allows researchers to process data from a large number of web pages. In recent years, this automated analysis has quickly and effectively interpreted large bodies of extracted online data, thus promising valuable insights across different research areas [23].

Feldman and Sanger [26] defined text mining as extracting the corpus of the data and identifying patterns and relationships in the textual data automatically. In other words, it is a process of extracting meaningful information pieces and subsequently applying algorithms to the extracted data and deriving structured variables for further analysis [27]. Text mining focuses on areas such as retrieving information, classifying and clustering texts, natural language processing, and so on. With the growing availability and popularity of social media platforms, sentiment analysis has emerged as a novel research area within text analytics in recent years [26,28]. Traditionally, sentiment analysis is about whether someone has a positive, neutral, or negative opinion toward something. In the context of social media, sentiment analysis aims to determine the opinion polarity of online reviews made by internet users toward products and services [28]. As an automated information obtaining technique, sentiment analysis can find the hidden patterns embedded in reviews, blogs, and tweets. It is extremely valuable to obtain this knowledge, as the opinions expressed within social media networks are genuine [29]. We observed that these affective opinions are easily understood, and they become the basis of decision making. Although sentiment analysis within text analytics has been applied in the political science, marketing, and consumer behavior fields, it has rarely been used to extract meaningful information from online data on health-related issues.

Researchers have applied new methods to analyze the contents and sentiments of YouTube comments. For example, Severyn et al [2] proposed a shallow syntactic structure to test and predict comment types and their polarity in English and Italian. They believe that this structure outperforms the traditional approach, such as the bag-of-words model, in terms of mining opinions. HarVis was introduced by Ahmad et al [4] as a tool to facilitate YouTube content acquisition, data processing, and visualization on any topic. Thelwall [3] developed comment term frequency comparison in order to investigate YouTube video topics as a novel social media analytics approach.

Sentiment analysis is a trending topic among YouTube video comments studies. One study investigated co-commenting behavior on K-pop videos by analyzing the weighted frequency and weighted sentiment scores of the co-comments. The results indicated that a large number of co-comments are positive, which impacted the co-commenting behavior in the K-pop video community [30]. Another study used SentiWordNet to analyze the comment ratings on the YouTube video platform. The findings showed that community feedback with term features is an indicator of the community acceptance of the comments [31]. This study will apply text mining techniques to extract YouTube healthy eating video comments and interpret them in order to understand people's perceptions and sentiments related to healthy eating.

Methods

Video and Comments Selection

This study analyzed comments scraped from YouTube related to healthy eating videos to investigate the perceptions and sentiments of YouTube audiences. It is set in Malaysia, where 11% of Malaysians have diabetes, the highest rate of incidence in Asia and one of the highest in the world. We are motivated

to understand the reasons for this health care predicament. We thus intend to examine healthy eating behaviors in this country. Given the enormous volume of YouTube video comments, we were able to gather data concentrated on healthy eating. Hence, a systematic search was conducted to select comments for analysis. The key phrase "healthy eating in Malaysia" was entered into the YouTube search engine. With the help of the filter function, videos were selected and ranked by relevance in descending order. The criteria for selecting videos in this study are the relevance of YouTube video contents of healthy eating in Malaysia, the number of each video's views, and the number of comments generated by commenters. The authors watched the videos from the first 5 consecutive results pages in order to select all of the relevant videos. They progressed through the rest of the list until the searched videos became totally unrelated. Following the steps by Meldrum et al [19], videos pertaining to non-Malaysian food, videos in languages other than English, videos targeting specific audiences, and videos that had disabled the commenting feature were excluded. Additionally, videos with fewer than 50 comments were excluded. In total, 10 videos remained after the authors independently screened and recorded the titles and links of the qualified videos. Replies to the existing comments and comments left by the video's creators were included as this content analysis focused on all of the community members' opinions on healthy eating. Overall, 5756 comments and replies posted under the 10 videos were scraped from YouTube [32] and transferred to an Excel spreadsheet (Microsoft Corporation). The authors read through the dataset and removed data entries such as #NAME#, external links, and advertisements. This data cleansing process returned 4654 data entries for the content analysis. Table 1 summarizes the videos included in this study. Similar to previous studies [17,19,33], as this study involved anonymous, publicly available data, it was deemed as exempt by the human ethics committee of Taylor's University.

Table 1. Overview of selected YouTube videos.

Title	Views, n	Comments, n
How I Eat Healthy on a Low Budget! (Cheap & Clean) [34]	1,197,933	1815
Must Eat "Free" Foods to Stay Slim [35]	1,152,241	745
Dieting Mistakes—Why You're Not Losing Weight! [36]	1,034,300	872
My EAT CLEAN Meal Plan (Full Recipes) [37]	577,141	373
It's Tough Dieting in Malaysia [38]	534,511	877
Healthy Foods That Can Make You GAIN WEIGHT [39]	436,489	668
Budget Meal Prep As a College Student! [40]	127,003	103
The Ultimate MALAYSIAN Healthy Food Swaps — Eat This. Not That [41]	52,418	196
We Try Eating Healthy for 2 Weeks — SAYS CubaTry [42]	39,959	53
What I Eat in a Day in Malaysia (video currently inaccessible)	25,552	54

Data Analysis

This study used a computer-assisted content analysis package called Text Miner version 9.4 (SAS Institute Inc) to analyze the comments from selected YouTube videos related to healthy eating. This software combines textual and statistical analysis by focusing on the frequency of words in a corpus. For example,

homogeneous subsets of words are identified on their lexical basis. At the initial stage, the SAS software extracts, stems, and filters words, which is called text parsing in the data analysis process. After the YouTube comments are tokenized, the identified terms are listed in terms of word frequency (see Table 2). During the text parsing node, parts of speech such as

prepositions, pronouns, and auxiliary verbs are ignored. Text parsing facilitates the systematic splitting of texts into sets of controllable terms in the text corpus. By eliminating extraneous terms, the text filter node keeps the relevant and meaningful terms that are shown by their frequency of occurrence in the dataset. The increased signal-to-noise ratio enhances the quality measure of the dataset [43]. The two processes led to a robust

set of relevant terms for further analysis via the term frequency-inverse document frequency algorithm (see [Multimedia Appendix 1](#)). This algorithm retains terms that are deemed relevant to the study like “healthy,” “vegan,” “weight,” “workout,” etc, while removing stopwords like “the,” “a,” “on,” and “in,” etc.

Table 2. Excerpts of the term frequency document.

Term	attrstring ^a	Weight	Frequency	Keep
+ ^b eat	Alpha	0.2600599	610	Y
+ video	Alpha	0.2509651	444	Y
+ food	Alpha	0.2883606	486	Y
+ good	Alpha	0.2775832	368	Y
+ love	Alpha	0.3065190	282	Y
+ healthy	Alpha	0.3331854	271	Y
+ people	Alpha	0.3584516	245	Y
+ weight	Alpha	0.3598992	238	Y
+ know	Alpha	0.3606262	200	Y
joanna	Alpha	0.3550649	176	Y
+ diet	Alpha	0.3694043	213	Y
+ egg	Alpha	0.3739284	241	Y
+ buy	Alpha	0.3863306	220	Y
+ great	Alpha	0.3680809	172	Y
+ live	Alpha	0.3922955	162	Y
+ lose	Alpha	0.3916902	153	Y
+ time	Alpha	0.4046275	138	Y
+ tip	Alpha	0.3997993	124	Y

^aattrstring: in the Alpha attribute, numeric characters are stored as a string.

^b+ depicts parent term.

Text clustering was then performed on the term frequency document by successively splitting terms into mutually exclusive groups. The process was conducted using the latent semantic indexing procedure to group terms into higher order semantic structures [44]. These groups were constructed based on similar forms (or words). The latent semantic indexing procedure in this study used the singular value decomposition (SVD) algorithm (see [Multimedia Appendix 2](#)) to reduce the terms in [Table 2](#) into a set of manageable clusters. Thus, the topics/themes are as revealed in [Table 3](#). The results of the

clustering via SVD on the term frequency document were set to generate enough SVD dimensions (k) for further analysis. The greater the number of dimensions (k), the higher the resolution to the term frequency clustered. In this study, k was set to 50, which was the default setting in the SAS software. The k-dimensional subspace was then generated from the cluster analysis via SVD. The cluster frequency root mean square standard deviation shown in [Table 3](#) shows that the derived clusters via SVD were well manifested and optimal as the values are close to 0.

Table 3. Summary of the text clusters.

Cluster ID	Cluster description	n (%)	RMS ^a SD
A12	+ ^b love awesome lol +true joanna ming +diet omg +work malaysia	416 (15.00)	0.103737
A18	+video +love joanna videos soh informative helpful ur +help +watch +channel +weight	369 (13.00)	0.125160
A11	+food +healthy +meat foods +protein +animal +eat +cheap +vegan +know veggies afford	322 (11.99)	0.127740
A17	+people eggs caged chickens animals understand dont +comment +vegan +bad +stop +chicken	341 (11.99)	0.133414
A13	+fat +budget +buy +low calories expensive +organic water +healthy +want foods	287 (9.99)	0.134404
A25	+good best better first advice +girl +body +smart +fat +gain eating “a lot of”	247 (9.00)	0.125705
A15	+great tips +video “great video” +rice “great tips” brown +tip awesome +white joanna looking	234 (8.01)	0.118946
A14	+true +malaysian +food malaysia +organic nasi +diet foods mamak lemak +exercise lah	195 (7.00)	0.124926
A19	butter +peanut +story +sugar watching +time coconut +avocado based +small +old +channel	183 (7.00)	0.132021
A22	+weight +lose +workout +week kg lost frozen +fresh +gym veggies +hot +buy	198 (7.00)	0.130526

^aRMS: root mean square.

^b+ depicts parent term.

Results

Cluster

This section describes the results of applying text mining methods to the topic of healthy eating in YouTube videos. Table 3 presents the major themes, sometimes called dimensions, that emerged from the data analysis. There were 10 clusters identified with regard to food ingredients, food price, food choice, food portion, well-being, cooking, and culture in the concept of healthy eating. These clusters are reflected in the most frequent key terms used by the YouTube commenters. The key terms were automatically selected on the basis of their occurrence and co-occurrence. The authors read through the key terms and sentences extracted from YouTube videos in order to make sense of the clusters categorized by the software.

Cluster A12: +love awesome lol +true joanna ming +diet omg +work malaysia

This cluster is mentioned in 15.00% (698/4654) of comments related to healthy eating. Many comments were related to the commenters' opinions of YouTube videos in the context of healthy eating in Malaysia. They expressed their feelings and gratitude toward the video creators by commenting “love,” “awesome,” and “thank you for sharing.”

Cluster A18: +video +love joanna videos soh informative helpful ur +help +watch +channel +weight

In total, 13.00% (605/4654) of comments gleaned from the YouTube videos contribute to cluster A18. Similar to cluster A12, people expressed their point of view on the usefulness of YouTube videos. Key terms were “informative” and “helpful.” A typical example of this cluster follows:

Thanks so much for this video, it is very informative!

Cluster A11: +food +healthy +meat foods +protein +animal +eat +cheap +vegan +know veggies afford

This cluster demonstrated that animal rights were mentioned. People who go vegan tend to want a healthy lifestyle. Others

believe humans are omnivores, but they are concerned with animal cruelty during the production process. A representative comment follows:

Humans are omnivore beings, there's nothing wrong or evil with eating meat. The way they are incarcerated and killed is made the way it is to make it cheaper and more profitable for the companies who produce them. It might not be the kindest way to deal with living beings, but it does make the process cheaper, taking food for more people's tables.

Cluster A17: +people eggs caged chickens animals understand don't +comment +vegan +bad +stop +chicken

This cluster was mentioned in 11.99% (558/4654) of comments related to healthy eating. A large number of YouTube commenters buy free-range chicken eggs to support animal welfare, whereas others cannot afford cage-free eggs as caged chicken eggs are cheaper. The emphasis is on food price. The argument of animal rights divided the commenters into two groups. Some are concerned about animal cruelty in relation to caged chickens. Others expressed their understanding of animal rights but explained that they cannot afford healthy eggs that are produced by free-range local farms. One of the most representative sentences under cluster A17 follows:

All I hear in the comments is “privilege!” I am a supporter of cruelty free products and natural ingredients but we have to be realistic about how the world works. The poorer you are (at least in the states) the higher risk you have for being unhealthy and attracting diseases. There are literally people who have no access to fresh foods known as “food deserts” and live off of canned and processed food because of their socioeconomic status.

Cluster A13: +fat +budget +buy +low calories expensive +organic water +healthy +want foods

This cluster is mentioned in 9.99% (465/4654) of YouTube comments. The commenters love the video, and they can relate to the video personally. Most people agree that we need to eat organic food. Some said that they cannot afford it. A number of people think that organic is simply a marketing term used by industries to make profits.

Yes, organic food is a lot more expensive and not affordable for everyone. If you like buying organic food and your opinion is that it is better then you should. Just know that it is not more nutritious; the taste is 100% objective; depending on where you get your organic food from it may not be sustainable and may use chemicals you don't normally think of as organic; you are also paying about 30% more for no reason other than the fact they put an organic sticker on it.

Cluster A25: +good best better first advice +girl +body +smart +fat +gain eating “a lot of”

This cluster deals with people's perception of YouTube videos, which are “good,” “better,” and “smart.”

Cluster A15: +great tips +video “great video” +rice “great tips” brown +tip awesome +white joanna looking

A number of comments contained the commenters' opinions of YouTube videos and video contents. As shown in this cluster, the key terms are “great” and “great tips.” People expressed their gratitude for the method of mixing brown rice and white rice, as suggested by YouTube creator Joanna. Many people support cooking and preparing meals at home. Some said that fast food is cheaper than homemade meals.

This white rice/brown rice mix tip is awesome!! Making homemade energy bars is a great option. You know precisely what went in it.

Cluster A14: +true +malaysian +food malaysia +organic nasi +diet foods mamak lemak +exercise lah

This cluster deals with the perceptions of Malaysian food in terms of healthy eating. Fat, sugar, and oils are most frequently mentioned in the YouTube comments. People believe that Malaysian food is high in calories and carbohydrates. People associated sugar with Malaysian food as well. In addition, it is tough to diet in Malaysia. Mamak (comfort food) restaurants are open 24/7, making it hard to resist Malaysian food. In other words, the cultural factor becomes a barrier to healthy eating in Malaysia. A typical comment follows:

Woww im so proud =))) I'm trying to follow your vidoes to eat healthier and to get up and exercise... You know how hard it is being a Malaysian because we love food so much ;)

Cluster A19: butter +peanut +story +sugar watching +time coconut +avocado based +small +old +channel

In this cluster, people associated healthy eating with food choices. Similar to a previous study [14], fruits are the most commonly mentioned healthy food. Key terms are coconut and avocado. An example follows:

I eat an avocado maybe one time a week as a meal with a piece of toast and an egg. I think avocados are great, just a once in a while thing tho.

Cluster A22: +weight +lose +workout +week kg lost frozen +fresh +gym veggies +hot +buy

This cluster illustrates the relationship between healthy eating and weight management. Commenters expressed their points of view on the challenges and barriers to healthy eating. The focus is that Malaysians find it very hard to eat on a diet; therefore, it is difficult to experience weight loss. Reasons such as delicious food choices are included. Exercising does not keep the body in shape as people go to Mamak restaurants after their workout. An example of a cluster A22 comment follows:

Before I came to malaysia, I did my diet as usual, but when i'm in malaysia I totally ruin my diet. Can't resist mee goreng mamak and many malaysian foods.

This cluster also deals with food-storing methods. People express their views on frozen vegetables and fresh vegetables. A lot of people believe that frozen vegetables contain more nutrients than fresh vegetables. A typical comment follows:

Nutrients may be lost if frozen vegetables are slowly defrosted. i have always been told by nutritionists that frozen is healthier than fresh.

A significant degree of convergence was found between the different clusters. This suggests that YouTube comments are likely to fall into more than one category. For example, food price was mentioned in clusters A11 and A13. Cultural factors were discussed in clusters A12 and A14. Food choices and ingredients related to healthy eating were included in clusters A11, A17, and A19. In general, the key terms related to selected YouTube videos contained positive sentiments such as “good” (mentioned 326 times), “great” (257 times), “love” (423 times), and “keep up with the good work” (19 times). Attitudes toward healthy eating are generally positive, as these clusters indicate. These results showed that research question 2 with regard to interpreting the sentiments of healthy eating comments has been addressed.

Based on Table 3, each cluster was manifested inside the derived subspace (see the root mean square standard deviation); 7 clusters were plotted on a Cartesian coordinate system, and 3 clusters (A12, A18, and A25) mainly related to the usefulness and favorability of videos were not considered for further analysis. In this Cartesian coordinate system, the distance between the clusters was the space generated during the SVD procedure. Clusters with shorter distances between them depict closer relationships within their semantic structures and vice versa. The results of the factor analysis showed that the data were appropriate for this study, given the Kaiser-Meyer-Olkin measure of sampling adequacy value of .879 [45]. A Bartlett

test of sphericity was significant ($P < .001$). Principal component analysis revealed that one factor was extracted and it accounted for 60.749% of the total variance. The Cronbach alpha value for the 7 items was .878, indicating a satisfactory level of reliability [46]. The t values in the results indicate that the critical ratios for the parameter estimates were significant at a .05 level. This result shows that convergent validity and the unidimensionality of each item met the satisfactory requirements [47]. Several model fit measures were employed to assess the model's overall goodness of fit. The results in Table 4 showed an adequate model fit, indicating that the model was acceptable [45].

Subsequently, the confirmatory factor analysis test was conducted on the clusters to examine the relationships of the clusters derived from the unstructured data pertaining to healthy eating. The measurement model was used to test the validity and reliability of the healthy eating determinants in this study. Confirmatory factor analysis was performed using SPSS Amos version 20 for Windows (IBM Corporation), and the results are shown in Figure 1, indicating that all of the healthy eating determinants have positive relationships with healthy eating. Table 5 summarizes the associations of the determinants in the measurement model.

Table 4. Goodness-of-fit indices.

SEM ^a indicators	Criteria	Results
Chi-square	—	13.395
Chi-square/degree of freedom ratio	<2	0.957
P value	>.05	.496
GFI ^b	>0.9	0.926
CFI ^c	>0.9	1.000
NFI ^d	>0.9	0.933
RMR ^e	close to 0	0.000
RMSEA ^f	<0.08	0.000

^aSEM: structural equation modeling.

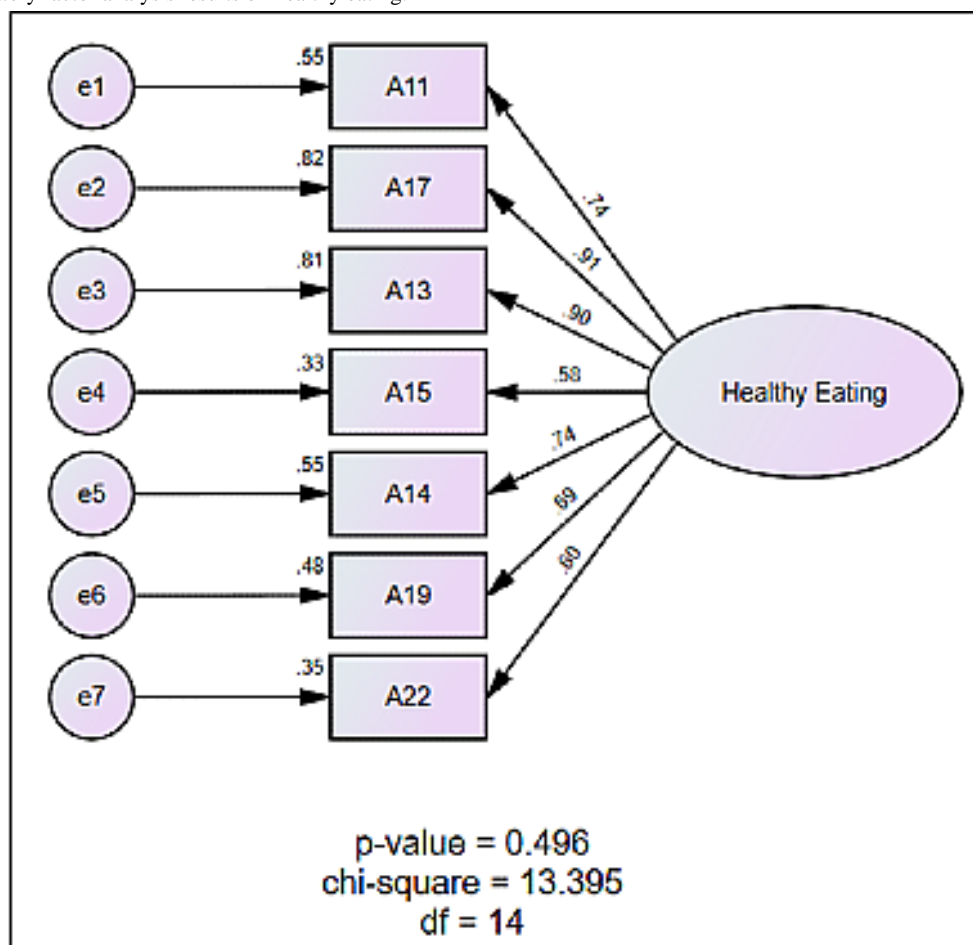
^bGFI: goodness-of-fit index.

^cCFI: comparative fit index.

^dNFI: normed fit index.

^eRMR: root mean square residual.

^fRMSEA: root mean square error of approximation.

Figure 1. Confirmatory factor analysis results on healthy eating.**Table 5.** Summary of the structural equation modeling results.

Path	Estimate	SE ^a	CR ^b	P value
A11<---Healthy eating	1.000	—	—	—
A17<---Healthy eating	0.926	0.144	6.443	<.001
A13<---Healthy eating	0.864	0.135	6.388	<.001
A15<---Healthy eating	0.763	0.191	3.987	<.001
A14<---Healthy eating	0.920	0.177	5.201	<.001
A19<---Healthy eating	0.772	0.160	4.828	<.001
A22<---Healthy eating	0.728	0.177	4.120	<.001

^aSE: standard error.

^bCR: critical ratio.

Discussion

Principal Findings

This study is one of the first attempts to identify the perceptions of healthy eating by analyzing a large corpus of data extracted from YouTube videos. Using content and sentiment analysis assisted by text analytics software, this study uncovered thematic clusters that indicate how people interpret healthy eating and what their eating behaviors are. Food choice, food price, cooking method, cultural influence, and weight management are identified as semantic clusters. A principal finding of this study

is that people hold complex and multifaceted beliefs about healthy eating in the context of YouTube videos. As suggested by Bisogni and colleagues [7], a set of beliefs may not be judged as correct or incorrect according to the scientists' standards. People also have different interests in the context of healthy eating, and they vary in their ways of dealing with changing information.

The concept of healthy eating is fairly consistent with the other studies' findings. That is, healthy eating is always described in terms of foods, namely fruits and vegetables (clusters A19 and A22). It seems that fruits and vegetables are the epitome of healthy foods. Healthy eating is regarded as eating more fruits

and vegetables, having a balanced diet, and consuming a variety of foods. People should limit their intake of high-caloric foods and avoid processed food [6]. Despite similarities with the previous studies, this study found that commenters are less likely to describe healthy eating directly, such as through nutrition. One possible explanation can be related to the nature of commenting on YouTube videos. The video creators mention specific food, and the viewers' immediate reaction would be to the food itself; hence the comments are intuitively related to the food mentioned in the videos.

This study has meaningfully categorized the determinants of healthy eating from both individual and collective aspects. A particularly interesting and potentially important insight from this study is that people's perceptions of healthy eating comprise social, economic, and physical well-being and moral factors (clusters A17 and A22). Free-range chicken eggs and caged chicken eggs are the most mentioned key terms in cluster A17. Animals deserve to live their lives free from suffering and exploitation. People who support animal rights buy free-range eggs. However, socioeconomically disadvantaged people can afford caged eggs only. As also seen in the study by Lu and Gursoy [8], the financial restriction factor lessens an individual's control over conducting a given behavior. In other words, despite a favorable perception of healthy eating, people may not purchase commonly recognized healthy food for a premium price. The study results indicated that food price as an economic determinant influences people's perceptions of healthy eating. More negative sentiments are expressed about healthy food prices. Weight concerns are associated with healthy eating. It is not surprising to see that people understand the importance of healthy eating with regard to physical well-being. This study has illustrated the priority of healthy eating as being related to the benefits of this behavior, such as weight loss, better appearance, and improved quality of life. Another key determinant identified in this study is the environmental factor. Studies have revealed that food service menu plans and the food available on campus, in addition to food stores and restaurants, contribute to a healthy lifestyle [13]. The physical environment, including home, school, and fast food establishments, plays an important part in influencing young people's eating behaviors [11]. Our study bears a close resemblance to these two studies. The key terms from cluster A15 indicated that people associated homemade food with healthy food. College students tend to prepare their food, and they avoid fast food sold on campus. One cultural factor was identified in this study. Consistent with the study findings of Bisogni et al [7], resources and environment prevented people from eating healthily. The study identified the reasons why Malaysians cannot always act on eating healthily, such as food taste, variety, and availability. In addition, the structural equation modeling results provided valuable insights into understanding the determinants that affect healthy eating practices.

Implications

This study contributes to the understanding of healthy eating behavior by examining a large volume of online data obtained from YouTube videos and fills the gap in previous research regarding healthy eating in the context of social media. It provides a comprehensive picture of healthy eating. The holistic

view includes the perceptions, determinant factors, and benefits and barriers to healthy eating. This study highlights the fit of using content analysis while analyzing healthy eating-related YouTube video comments. Quantitative approaches are restricted to measuring aspects, like popularity [18]. This qualitative approach allows researchers to have an in-depth understanding of how people interpret and disseminate information regarding healthy eating. In addition, YouTube video comments are generally genuine personal reactions made by the commenters. Compared with the socially desirable answers obtained from surveys/focus groups, this social media data produces theoretically and empirically sound results [48]. Moreover, in comparison with the traditional sample size and response rate, this study offers significant value to the existing literature of health-related studies by investigating the rich and diverse social media data gathered from YouTube. This study sheds light on the understanding of the underlying social structure and dynamics in the context of healthy eating. People from socioeconomically affluent communities have the availability of healthy food from local farms. Some people choose to buy caged chicken eggs even though they know that it is morally wrong. This study offers a detailed picture of the impact of social and economic factors on healthy eating.

This study may assist public health professionals in making effective public health campaigns. Transcending geographical and regulatory boundaries, the internet provides the public with a source of reference material [23,49,50]. This study found that the distinction between experience and expertise is blurred with regard to healthy eating comments. Therefore, it is imperative for health professionals to use social media platforms to disseminate accurate and credible health information to lay audiences. In other words, public health professionals work on posting and replying to conversations when appropriate through comments and sharing materials with members of the social media community. Moreover, the salient findings of this study can provide nutrition educators and health professionals with meaningful and useful ideas. These professionals are advised to deliver nutrition information on calories, macronutrients (fat, protein, and carbohydrate), and micronutrients (vitamins and minerals) to the public in a concise manner. Public health campaigns could be employed to promote healthy eating by establishing appropriate interventions tailored to the targeted audience. For instance, providing affordable and appealing healthy food in schools may serve to increase the students' willingness to eat healthily. Sustainable diets may be an alternative to promoting public health with various governmental and social support.

Limitation and Future Studies

Some study limitations should be noted. The sample of YouTube videos was selected based on relevance and the number of views and comments. The authors conducted informal searches for videos related to healthy eating during the sampling; however, using limited key phrases when searching does not guarantee a complete and representative sample of YouTube videos. Further investigation using more videos and comments may reveal new findings related to healthy eating.

The study context of healthy eating in Malaysia is another limitation. Examining the comments from other cultures would increase the generalizability of the study. The sampling bias of YouTube video comments cannot be avoided as these comments are broad but less focused. In addition, it may be beneficial if future studies made a comparison of online data from different social media platforms regarding similar topics. With the help of text analytics software, the study identified several thematic clusters. The authors selected each category after screening the corpus of the data. Such a classification can ignore some of the significant variations within each cluster. Future research is encouraged to study more comments in order to explore new categories and subcategories of healthy eating. This study did not examine the number of likes, which is an important parameter, leaving space for future research. The authors consider this study and concurrent research as a first step to understanding the perceptions of healthy eating, not as the end of the discussion.

Conclusion

There has been an increasing recognition that healthy food intake and balanced eating patterns play an important role in health and disease prevention. This study conducted an in-depth content analysis of YouTube comments. The text analytics method was employed as it is useful for discussing and exploring large-scale YouTube-specific phenomenon. This study provides 10 main categories related to healthy eating, including food choice, food price, cooking method, cultural influence, weight management, and so on. Structural equation modeling revealed there to be significant relationships between these categories and healthy eating. Through the lens of text analytics and sentiment analysis, our results suggest that people have a largely positive attitude toward healthy eating. This study contributes to the perceptions of healthy eating by categorizing the determinants, benefits, and barriers to healthy eating such as food choice, food price, weight management, and cultural influence. Future study is necessary to explore more of the categories, subcategories, and underlying concepts of healthy eating. The findings of this study provide support for public health professionals to allow them to better implement effective health promotion campaigns.

Acknowledgments

This work is funded by Crops for the Future Research Centre and University of Nottingham Malaysia Doctoral Training Partnership.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Term frequency-inverse document frequency algorithm.

[PDF File (Adobe PDF File), 384 KB - [publichealth_v6i4e19618_app1.pdf](#)]

Multimedia Appendix 2

Singular value decomposition algorithm.

[PDF File (Adobe PDF File), 330 KB - [publichealth_v6i4e19618_app2.pdf](#)]

References

1. Deshpande S, Basil MD, Basil DZ. Factors influencing healthy eating habits among college students: an application of the health belief model. *Health Mark Q* 2009;26(2):145-164. [doi: [10.1080/07359680802619834](#)] [Medline: [19408181](#)]
2. Severyn A, Moschitti A, Uryupina O, Plank B, Filippova K. Multi-lingual opinion mining on YouTube. *Inf Proc Manag* 2016 Jan;52(1):46-60. [doi: [10.1016/j.ipm.2015.03.002](#)]
3. Thelwall M. Social media analytics for YouTube comments: potential and limitations. *Int J Soc Res Methodol* 2017 Sep 21;21(3):303-316. [doi: [10.1080/13645579.2017.1381821](#)]
4. Ahmad U, Zahid A, Shoaib M, AlAmri A. HarVis: an integrated social media content analysis framework for YouTube platform. *Inf Syst* 2017 Sep;69:25-39. [doi: [10.1016/j.is.2016.10.004](#)]
5. Ariyasriwatana W, Buente W, Oshiro M, Streveler D. Categorizing health-related cues to action: using Yelp reviews of restaurants in Hawaii. *New Rev Hypermedia Multimedia* 2014 Nov 28;20(4):317-340. [doi: [10.1080/13614568.2014.987326](#)]
6. Croll JK, Neumark-Sztainer D, Story M. Healthy eating: what does it mean to adolescents? *J Nutr Educ* 2001;33(4):193-198. [doi: [10.1016/s1499-4046\(06\)60031-6](#)] [Medline: [11953240](#)]
7. Bisogni CA, Jastran M, Seligson M, Thompson A. How people interpret healthy eating: contributions of qualitative research. *J Nutr Educ Behav* 2012;44(4):282-301. [doi: [10.1016/j.jneb.2011.11.009](#)] [Medline: [22732708](#)]
8. Lu L, Gursoy D. Does offering an organic food menu help restaurants excel in competition? An examination of diners' decision-making. *Int J Hospital Manag* 2017 May;63:72-81. [doi: [10.1016/j.ijhm.2017.03.004](#)]
9. Willett WC, Sacks F, Trichopoulou A, Drescher G, Ferro-Luzzi A, Helsing E, et al. Mediterranean diet pyramid: a cultural model for healthy eating. *Am J Clin Nutr* 1995 Jun;61(6 Suppl):1402S-1406S. [doi: [10.1093/ajcn/61.6.1402S](#)] [Medline: [7754995](#)]

10. Guenther PM, Reedy J, Krebs-Smith SM. Development of the Healthy Eating Index 2005. *J Am Diet Assoc* 2008 Nov;108(11):1896-1901. [doi: [10.1016/j.jada.2008.08.016](https://doi.org/10.1016/j.jada.2008.08.016)] [Medline: [18954580](https://pubmed.ncbi.nlm.nih.gov/18954580/)]
11. Taylor JP, Evers S, McKenna M. Determinants of healthy eating in children and youth. *Can J Public Health* 2005;96 Suppl 3:S20-S26. [Medline: [16042160](https://pubmed.ncbi.nlm.nih.gov/16042160/)]
12. Shen Y, Clarke P, Gomez-Lopez IN, Hill AB, Romero DM, Goodspeed R, et al. Using social media to assess the consumer nutrition environment: comparing Yelp reviews with a direct observation audit instrument for grocery stores. *Public Health Nutr* 2019 Feb;22(2):257-264. [doi: [10.1017/S1368980018002872](https://doi.org/10.1017/S1368980018002872)] [Medline: [30406742](https://pubmed.ncbi.nlm.nih.gov/30406742/)]
13. Wechsler H, Devereaux RS, Davis M, Collins J. Using the school environment to promote physical activity and healthy eating. *Prev Med* 2000 Aug;31(2):S121-S137. [doi: [10.1006/pmed.2000.0649](https://doi.org/10.1006/pmed.2000.0649)]
14. Shepherd J, Harden A, Rees R, Brunton G, Garcia J, Oliver S, et al. Young people and healthy eating: a systematic review of research on barriers and facilitators. *Health Educ Res* 2006 Apr;21(2):239-257. [doi: [10.1093/her/cyh060](https://doi.org/10.1093/her/cyh060)] [Medline: [16251223](https://pubmed.ncbi.nlm.nih.gov/16251223/)]
15. Vizireanu M, Hruschka D. Lay perceptions of healthy eating styles and their health impacts. *J Nutr Educ Behav* 2018 Apr;50(4):365-371. [doi: [10.1016/j.jneb.2017.12.012](https://doi.org/10.1016/j.jneb.2017.12.012)] [Medline: [29478950](https://pubmed.ncbi.nlm.nih.gov/29478950/)]
16. Madden A, Ruthven I, McMenemy D. A classification scheme for content analyses of YouTube video comments. *J Documentation* 2013 Sep 02;69(5):693-714. [doi: [10.1108/jd-06-2012-0078](https://doi.org/10.1108/jd-06-2012-0078)]
17. Lewis SP, Heath NL, Sornberger MJ, Arbuthnott AE. Helpful or harmful? An examination of viewers' responses to nonsuicidal self-injury videos on YouTube. *J Adolesc Health* 2012 Oct;51(4):380-385. [doi: [10.1016/j.jadohealth.2012.01.013](https://doi.org/10.1016/j.jadohealth.2012.01.013)] [Medline: [22999839](https://pubmed.ncbi.nlm.nih.gov/22999839/)]
18. Wendt LM, Griesbaum J, Kölle R. Product advertising and viral stealth marketing in online videos. *Aslib Journal of Info Mgmt* 2016 May 16;68(3):250-264. [doi: [10.1108/ajim-11-2015-0174](https://doi.org/10.1108/ajim-11-2015-0174)]
19. Meldrum S, Savarimuthu BT, Licorish S, Tahir A, Bosu M, Jayakaran P. Is knee pain information on YouTube videos perceived to be helpful? An analysis of user comments and implications for dissemination on social media. *Digit Health* 2017;3:1-18 [FREE Full text] [doi: [10.1177/2055207617698908](https://doi.org/10.1177/2055207617698908)] [Medline: [29942583](https://pubmed.ncbi.nlm.nih.gov/29942583/)]
20. Choi GY, Behm-Morawitz E. Giving a new makeover to STEAM: establishing YouTube beauty gurus as digital literacy educators through messages and effects on viewers. *Comput Hum Behav* 2017 Aug;73:80-91. [doi: [10.1016/j.chb.2017.03.034](https://doi.org/10.1016/j.chb.2017.03.034)]
21. Ferchaud A, Grzeslo J, Orme S, LaGroue J. Parasocial attributes and YouTube personalities: exploring content trends across the most subscribed YouTube channels. *Comput Hum Behav* 2018 Mar;80:88-96. [doi: [10.1016/j.chb.2017.10.041](https://doi.org/10.1016/j.chb.2017.10.041)]
22. Zhang X, Baker K, Pember S, Bissell K. Persuading me to eat healthy: a content analysis of YouTube public service announcements grounded in the health belief model. *Southern Comm J* 2017 Feb 02;82(1):38-51. [doi: [10.1080/1041794x.2016.1278259](https://doi.org/10.1080/1041794x.2016.1278259)]
23. Bicquelet A. Using online mining techniques to inform formative evaluations: an analysis of YouTube video comments about chronic pain. *Evaluation* 2017 Jul 12;23(3):323-338. [doi: [10.1177/1356389017715719](https://doi.org/10.1177/1356389017715719)]
24. Presser S, Couper MP, Lessler JT, Martin E, Martin J, Rothgeb JM, et al. Methods for testing and evaluating survey questions. *Publ Opin Q* 2004 Apr 22;68(1):109-130. [doi: [10.1093/poq/nfh008](https://doi.org/10.1093/poq/nfh008)]
25. Pope C, Ziebland S, Mays N. Qualitative research in health care. Analysing qualitative data. *BMJ* 2000 Jan 08;320(7227):114-116 [FREE Full text] [doi: [10.1136/bmj.320.7227.114](https://doi.org/10.1136/bmj.320.7227.114)] [Medline: [10625273](https://pubmed.ncbi.nlm.nih.gov/10625273/)]
26. Feldman R, Sanger J. *The Text Mining Handbook: Advanced Approaches in Analyzing Unstructured Data*. New York: Cambridge University Press; 2007.
27. Siering M, Deokar AV, Janze C. Disentangling consumer recommendations: explaining and predicting airline recommendations based on online reviews. *Decis Supp Syst* 2018 Mar;107(1):52-63. [doi: [10.1016/j.dss.2018.01.002](https://doi.org/10.1016/j.dss.2018.01.002)]
28. Mäntylä MV, Graziotin D, Kuutila M. The evolution of sentiment analysis—a review of research topics, venues, and top cited papers. *Comput Sci Rev* 2018 Feb;27(1):16-32. [doi: [10.1016/j.cosrev.2017.10.002](https://doi.org/10.1016/j.cosrev.2017.10.002)]
29. Mostafa MM. More than words: social networks' text mining for consumer brand sentiments. *Exp Syst Appl* 2013 Aug;40(10):4241-4251. [doi: [10.1016/j.eswa.2013.01.019](https://doi.org/10.1016/j.eswa.2013.01.019)]
30. Song M, Jeong YK, Kim HJ. Identifying the topology of the K-pop video community on YouTube: a combined co-comment analysis approach. *J Assn Inf Sci Tec* 2015 Apr 02;66(12):2580-2595. [doi: [10.1002/asi.23346](https://doi.org/10.1002/asi.23346)]
31. Siersdorfer S, Chelaru S, Nejdil W, San Pedro J. How useful are your comments? Analyzing and predicting YouTube comments and comment ratings. 2010 Presented at: Proceedings of the 19th International Conference on World Wide Web, WWW 2010; 2010; Raleigh. [doi: [10.1145/1772690.1772781](https://doi.org/10.1145/1772690.1772781)]
32. Comments and replies scraped from YouTube. URL: <https://github.com/philbot9/youtube-comment-scraper-cli> [accessed 2020-09-27]
33. Osadchiy V, Mills JN, Eleswarapu SV. Understanding patient anxieties in the social media era: qualitative analysis and natural language processing of an online male infertility community. *J Med Internet Res* 2020 Mar 10;22(3):e16728 [FREE Full text] [doi: [10.2196/16728](https://doi.org/10.2196/16728)] [Medline: [32154785](https://pubmed.ncbi.nlm.nih.gov/32154785/)]
34. How I Eat Healthy on a Low Budget! (Cheap & Clean). URL: <https://www.youtube.com/watch?v=QKpBNp5Lj0g>
35. Must Eat “Free” Foods to Stay Slim. URL: <https://www.youtube.com/watch?v=Rg98-7m0DoY> [accessed 2020-09-21]
36. Dieting Mistakes—Why You're Not Losing Weight!. URL: https://www.youtube.com/watch?v=8jk-y-f_5Mw [accessed 2020-09-21]

37. My EAT CLEAN Meal Plan (Full Recipes). URL: <https://www.youtube.com/watch?v=6j4uecVkbOw> [accessed 2020-09-21]
38. It's Tough Dieting in Malaysia. URL: <https://www.youtube.com/watch?v=NwYu9iboyaA> [accessed 2020-09-21]
39. Healthy Foods That Can Make You GAIN WEIGHT. URL: <https://www.youtube.com/watch?v=r1LgRCjXJOY> [accessed 2020-09-21]
40. Budget Meal Prep As a College Student!. URL: <https://www.youtube.com/watch?v=7gjS32DMmEo> [accessed 2020-09-21]
41. The Ultimate MALAYSIAN Healthy Food Swaps — Eat This. Not That. URL: <https://www.youtube.com/watch?v=YZxCc6xMPXI> [accessed 2020-09-21]
42. We Try Eating Healthy for 2 Weeks — SAYS CubaTry. URL: <https://www.youtube.com/watch?v=bbByRx1gm-8> [accessed 2020-09-21]
43. Kim Y, Huang J, Emery S. Garbage in, garbage out: data collection, quality assessment and reporting standards for social media data use in health research, infodemiology and digital disease detection. *J Med Internet Res* 2016;18(2):e41 [FREE Full text] [doi: [10.2196/jmir.4738](https://doi.org/10.2196/jmir.4738)] [Medline: [26920122](https://pubmed.ncbi.nlm.nih.gov/26920122/)]
44. Zhang W, Yoshida T, Tang X. A comparative study of TF*IDF, LSI and multi-words for text classification. *Exp Syst Appl* 2011 Mar;38(3):2758-2765. [doi: [10.1016/j.eswa.2010.08.066](https://doi.org/10.1016/j.eswa.2010.08.066)]
45. Hair J, Black WC, Babin BJ, Anderson R. *Multivariate Data Analysis*. 7th edition. Upple Saddle River: Prentice-Hall; 2010.
46. Nunnally J. *Psychometric Theory*. 2nd Edition. New York: McGraw-Hill; 1988.
47. Anderson JC, Gerbing DW. Structural equation modeling in practice: a review and recommended two-step approach. *Psychol Bull* 1988;103(3):411-423. [doi: [10.1037/0033-2909.103.3.411](https://doi.org/10.1037/0033-2909.103.3.411)]
48. Miller E. Content analysis of select YouTube postings: comparisons of Reactions to the Sandy Hook and Aurora shootings and Hurricane Sandy. *Cyberpsychol Behav Soc Netw* 2015 Nov;18(11):635-640. [doi: [10.1089/cyber.2015.0045](https://doi.org/10.1089/cyber.2015.0045)] [Medline: [26379103](https://pubmed.ncbi.nlm.nih.gov/26379103/)]
49. Rivas R, Sadah SA, Guo Y, Hristidis V. Classification of health-related social media posts: evaluation of post content-classifier models and analysis of user demographics. *JMIR Public Health Surveill* 2020 Apr 01;6(2):e14952. [doi: [10.2196/14952](https://doi.org/10.2196/14952)] [Medline: [32234706](https://pubmed.ncbi.nlm.nih.gov/32234706/)]
50. Moon RY, Mathews A, Oden R, Carlin R. Mothers' perceptions of the internet and social media as sources of parenting and health information: qualitative study. *J Med Internet Res* 2019 Jul 09;21(7):e14289 [FREE Full text] [doi: [10.2196/14289](https://doi.org/10.2196/14289)] [Medline: [31290403](https://pubmed.ncbi.nlm.nih.gov/31290403/)]

Abbreviations

HEI: Healthy Eating Index

SVD: singular value decomposition

Edited by G Eysenbach; submitted 25.04.20; peer-reviewed by J Wilroy, M Torii; comments to author 19.07.20; revised version received 04.08.20; accepted 10.08.20; published 01.10.20.

Please cite as:

Teng S, Khong KW, Pahlevan Sharif S, Ahmed A

YouTube Video Comments on Healthy Eating: Descriptive and Predictive Analysis

JMIR Public Health Surveill 2020;6(4):e19618

URL: <https://publichealth.jmir.org/2020/4/e19618>

doi: [10.2196/19618](https://doi.org/10.2196/19618)

PMID: [33001036](https://pubmed.ncbi.nlm.nih.gov/33001036/)

©Shasha Teng, Kok Wei Khong, Saeed Pahlevan Sharif, Amr Ahmed. Originally published in *JMIR Public Health and Surveillance* (<http://publichealth.jmir.org>), 01.10.2020. This is an open-access article distributed under the terms of the Creative Commons Attribution License (<https://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in *JMIR Public Health and Surveillance*, is properly cited. The complete bibliographic information, a link to the original publication on <http://publichealth.jmir.org>, as well as this copyright and license information must be included.

Original Paper

Geographic Differences in Cannabis Conversations on Twitter: Infodemiology Study

Jenna van Draanen¹, PhD, MPH; HaoDong Tao², BSc; Saksham Gupta³, BTECH; Sam Liu³, PhD

¹Department of Sociology, University of British Columbia, Vancouver, BC, Canada

²Department of Computer Science, University of Victoria, Victoria, BC, Canada

³School of Exercise Science, Physical & Health Education, University of Victoria, Victoria, BC, Canada

Corresponding Author:

Jenna van Draanen, PhD, MPH

Department of Sociology

University of British Columbia

6303 NW Marine Drive

Vancouver, BC, V6T1Z1

Canada

Phone: 1 778 751 9136

Email: jenna.van.draanen@ubc.ca

Abstract

Background: Infodemiology is an emerging field of research that utilizes user-generated health-related content, such as that found in social media, to help improve public health. Twitter has become an important venue for studying emerging patterns in health issues such as substance use because it can reflect trends in real-time and display messages generated directly by users, giving a uniquely personal voice to analyses. Over the past year, several states in the United States have passed legislation to legalize adult recreational use of cannabis and the federal government in Canada has done the same. There are few studies that examine the sentiment and content of tweets about cannabis since the recent legislative changes regarding cannabis have occurred in North America.

Objective: To examine differences in the sentiment and content of cannabis-related tweets by state cannabis laws, and to examine differences in sentiment between the United States and Canada between 2017 and 2019.

Methods: In total, 1,200,127 cannabis-related tweets were collected from January 1, 2017, to June 17, 2019, using the Twitter application programming interface. Tweets then were grouped geographically based on cannabis legal status (legal for adult recreational use, legal for medical use, and no legal use) in the locations from which the tweets came. Sentiment scoring for the tweets was done with VADER (Valence Aware Dictionary and sEntiment Reasoner), and differences in sentiment for states with different cannabis laws were tested using Tukey adjusted two-sided pairwise comparisons. Topic analysis to determine the content of tweets was done using latent Dirichlet allocation in Python, using a Java implementation, LdaMallet, with Gensim wrapper.

Results: Significant differences were seen in tweet sentiment between US states with different cannabis laws ($P=.001$ for negative sentiment tweets in fully illegal compared to legal for adult recreational use states), as well as between the United States and Canada ($P=.003$ for positive sentiment and $P=.001$ for negative sentiment). In both cases, restrictive state policy environments (eg, those where cannabis use is fully illegal, or legal for medical use only) were associated with more negative tweet sentiment than less restrictive policy environments (eg, where cannabis is legal for adult recreational use). Six key topics were found in recent US tweet contents: fun and recreation (keywords, eg, love, life, high); daily life (today, start, live); transactions (buy, sell, money); places of use (room, car, house); medical use and cannabis industry (business, industry, company); and legalization (legalize, police, tax). The keywords representing content of tweets also differed between the United States and Canada.

Conclusions: Knowledge about how cannabis is being discussed online, and geographic differences that exist in these conversations may help to inform public health planning and prevention efforts. Public health education about how to use cannabis in ways that promote safety and minimize harms may be especially important in places where cannabis is legal for adult recreational and medical use.

(JMIR Public Health Surveill 2020;6(4):e18540) doi:[10.2196/18540](https://doi.org/10.2196/18540)

KEYWORDS

marijuana; social media; sentiment; cannabis; Twitter

Introduction

Social media platforms represent an important venue for studying emerging patterns in public health issues such as substance use because they can reflect trends in real time and display messages generated directly by users, giving a uniquely personal voice to analyses. This method of using social data to improve our understanding of public health is known as Infodemiology [1]. Twitter is a widely used social networking platform where users share messages in 280-character tweets (or 140-character tweets before October 2017), offering a rich venue for investigating public sentiment.

One of the main approaches to analyze unstructured text data from Twitter is sentiment of the tweets [2,3]. Sentiment analysis can determine whether an individual's attitude or perception toward a topic is positive, negative, or neutral. A second popular method of analyzing tweets is topic modeling, which refers to a technique that discovers the hidden semantic structure in a text corpus. Topic modeling can be particularly helpful in providing insights into the different themes present in the texts [4,5]. By applying these methods, emerging research has used Twitter data for public health surveillance including monitoring symptoms of depression [6], psychological distress [7], influenza transmission [8], lifestyle behaviors [9], and substance use trends [10,11].

Twitter data can be especially useful in highlighting emergent areas of concern in substance use research that are not detectable from other sources, and past studies have uncovered critical issues, for example, related to the use of Adderall by adolescents [10], procannabis content being disproportionately created and consumed by young minorities [12,13], and geographic variation in discussions about cannabis concentrate (dabs) [14]. Prior research in this area has begun to characterize the sentiment of cannabis-related tweets both manually [15,16] and using advanced information processing techniques [17]. Sentiment toward cannabis online has been characterized as dominantly procannabis, and this is especially the case in personal communications, which make up the strong majority of tweets about cannabis [17]. As the policy landscape related to cannabis is rapidly changing, so too may attitudes toward cannabis online, but this is currently unknown.

Several states in the United States have passed legislation to legalize adult recreational use of cannabis (eg, Colorado, Washington, California) and the federal government in Canada has done the same [18,19]. These legislative changes may be both reflecting and impacting public sentiment about cannabis use. For example, states that have less restrictive policies about cannabis use have historically been found to have a higher volume of cannabis-related tweets [14,20] and the volume of procannabis tweets has previously been found to increase postlegalization. Further, tweets from states with less restrictive policies are more positive and vary according to the local social and demographic trends [21]. Using 2016 data, Daniulaityte and colleagues [20] compared sentiment toward cannabis in

tweets by legality of cannabis at the state level and found statistically significant differences in the ratio of positive to negative tweets. States with recreational laws had a mean ratio of 4.64 (favoring procannabis tweets) and states where all consumption of cannabis was illegal had a ratio of 4.19 [20]. Similarly, positive sentiment in tweets about rosin (a cannabis concentrate) is up to 16 times higher in states allowing adult recreational use of cannabis compared with states where cannabis is illegal [22]. In the 3 years since the last sentiment analysis, the policy environment surrounding cannabis has changed dramatically and it is possible that users of Twitter have changed the way they talk about cannabis online as well; however, this is currently unknown.

Previous content analysis has indicated that themes among procannabis adolescent Twitter users included intent to use or craving; frequent, heavy, or regular use; health benefits and prolegalization; sex/romance; attractiveness or friendships; and current use [15]. A study of influential tweets (ie, tweets with a high number of re-tweets) about both alcohol and cannabis found that common themes included using marijuana or alcohol with friends, sex/romance, and tobacco or other drugs [11]. However, these content analyses had samples restricted to influential Twitter users and adolescents [12,13,15,23]. Another recent study of tweets from a more general sample captured 12 topics in cannabis-related tweets and also found polysubstance use to be a recurring topic, in addition to topics such as using cannabis, health and medical, cannabis industry, and legality (among others) [24].

Given that the way both governments and the general public are interacting with cannabis is rapidly changing in North America, and that Twitter data have been shown to illustrate trends in real time, it is timely to conduct an updated analysis of the sentiment and content of tweets about cannabis. The objectives of this study are, therefore, to examine differences in the sentiment and content of cannabis-related tweets by state cannabis laws and between the United States and Canada. To our knowledge, this is the first analysis that includes Canadian data and the first analysis to be conducted with data up to 2019.

Methods**Data Collection and Cleaning**

Tweets were collected from January 1, 2017, to June 17, 2019, using the Twitter Realtime Filter application programming interface (API) and a standard access token [25]. Tweets were streamed using a location box of the following longitude and latitude (–162.354635, 18.756125, –53.755999, 73.893030). We captured 576 million tweets. Twitter API used in this study captures a random sample of about 1% of all tweets in Canada and the United States in the designated period. University institutional review board approval was not required as the data set was limited to publicly available tweets. These tweets were stored in “.csv” files and resampled using custom Python script with Pandas library. Each tweet has 3 nonmandatory attributes to determine location by state or province: *tweetLocation* (an

identifiable address indicating the rough location from where the tweet was sent), and 2 geo coordinate attributes, namely, *Longitude* and *Latitude*. Because our research questions are fundamentally concerned with place-based legislation changes, we retained only tweets with location data in our data set. Tweets that were linked with location attributes were labeled using a custom-built dictionary that maps the location strings to the 2-letter state or province abbreviations. Tweets with geocoordinates only were labeled with reverse geocode lookup using Google Maps API.

In the US data set, 50 states and 1 federal district (District of Columbia) were grouped based on cannabis legal status [26]. These 3 groups include (1) Fully illegal states for both adult recreational and medical use (n=12; Alaska, Indiana, Iowa, Kansas, Kentucky, Missouri, North Carolina, Nevada, South Carolina, South Dakota, Tennessee, Wyoming); (2) legal for medical use only (n=30; Arkansas, Arizona, California [up to January 1, 2018], Connecticut, Delaware, Florida, Georgia, Hawaii, Idaho, Illinois, Louisiana, Maryland, Michigan [up to December 5, 2018], Minnesota, Mississippi, Montana, Nebraska, New Hampshire, New Jersey, New Mexico, New York, Ohio, Oklahoma, Pennsylvania, Rhode Island, Texas, Utah, Virginia, Vermont [up to June 30, 2018], West Virginia); and (3) legal for both adult recreational and medical use (n=11; Alabama, California [starting January 1, 2018], Colorado, District of Columbia, Massachusetts, Maine, Michigan [starting December 6, 2018], Vermont [starting July 1, 2018], North Dakota, Oregon, Washington). Three US states (Michigan, California, and Vermont) changed their cannabis regulatory policy during the data collection period and thus tweets from these 3 states were grouped into different categories depending on whether they were posted prelegalization or postlegalization.

Because Canada had no legal differences across provinces in cannabis law and only minor regulatory differences, variation in tweets across Canada by provincial legal status was not examined. Nationally, cannabis became legal for medical use in Canada in 2001 (with the Marijuana for Medical Purposes Regulations) and became legal for adult recreational consumption on October 17, 2018 with the passage of Bill C-45: Cannabis Act in June 2018 [18].

Classifying Marijuana Related Tweets

Tweets were classified as being cannabis-related using a set of keywords based on the method used by others in the field [27]. We translated the following search queries and conditions into regular expressions: “Weed,” “marijuana,” “cannabis,” “smoke AND (pot OR joint OR blunt OR mary jane),” “need AND (pot OR joint OR blunt),” “want AND (pot OR a blunt),” and “want AND a joint.” Furthermore, for queries with 2 search terms, the terms were required to be within 3 words of each other, as done in related studies [27]. In total, 1,200,127 tweets were classified as cannabis related: 1,149,137 from the United States and 50,990 from Canada.

Classifying Sentiment

Sentiment scoring for the tweets was done with VADER (Valence Aware Dictionary and sEntiment Reasoner) Sentiment, a lexicon and rule-based sentiment analysis tool [3]. VADER

analysis uses a predefined dictionary that maps on different words and lexicon features, acronyms, and slang to determine the positive or negative sentiment of a tweet [28]. Sentiment valence score increases with words with more positive sentiment (eg, happy, nice, good). The tweets were parsed through the VADER sentiment analysis to check for the words, emoticons, and slang that are present in the lexicon. VADER also gave importance to capital letters and exclamation marks. VADER calculated the proportion of positive, neutral, and negative sentiment scores for a tweet. A compound score was then calculated by summing the sentiment scores and normalizing the result. Sentiment scores can range between -1 (negative sentiment) and 1 (positive sentiment). Scores between -0.05 and 0.05 were considered neutral. Normalization was performed using the following formula: $z/\sqrt{(z^2+r)}$, where z is the value created after adding the valence scores of a tweet, and r is a normalization constant which is taken as 15 by default. The code for our analysis was made available online [29]. Classifying tweets associated with substance use using automated methods can be particularly difficult due to the use of slang and implied meanings [17]. A tweet's sentiment does not necessarily reflect the Twitter user's stance on cannabis usage; it instead reflects the emotionality in their words used to communicate about cannabis, thus positive sentiment is not the same as a pro-cannabis opinion, and likewise, negative sentiment is not analogous with an anti-cannabis perspective. The null hypotheses of no difference in proportions between groups of states defined by legal status and between the United States and Canada were tested with two-sided pairwise comparisons using Stata version 14.0 (StataCorp). Multiple comparisons were adjusted for using the Tukey method [30].

Topic Modeling

Topic analysis to determine the content of tweets was done using latent Dirichlet allocation (LDA) in Python, using a Java implementation, LdaMallet, with Gensim wrapper [31]. LDA is an unsupervised probabilistic model which generates mixtures of topics from a corpus of text. A topic is a probability distribution over every word found in the corpus. LDA works by looking at the word co-occurrences within the corpus of text, assuming that words that occur in the same corpus of text are more likely to be on the same topic than words that are not [32]. The UMass coherence matrices were used to measure topic coherence. A previous study has shown that this method achieved reasonable results when comparing the scores obtained by this measure with human scoring on a corpus of 300,000 health journal abstracts [4]. The model with the highest coherence score was chosen for analysis. We then used human judgment to validate the topics identified. The use of a human's perception has been previously used along with statistical methods to evaluate topic models using Twitter [33,34]. Specifically, we performed word and topic intrusion tasks. Word intrusion allows the analyst to measure how semantically *cohesive* the topics inferred by a model are and tests whether topics correspond to natural groupings for humans. Topic intrusion enabled the human subject to evaluate how well a topic model in a document as a mixture of topics agrees with human associations of topics with a document [33]. LDA

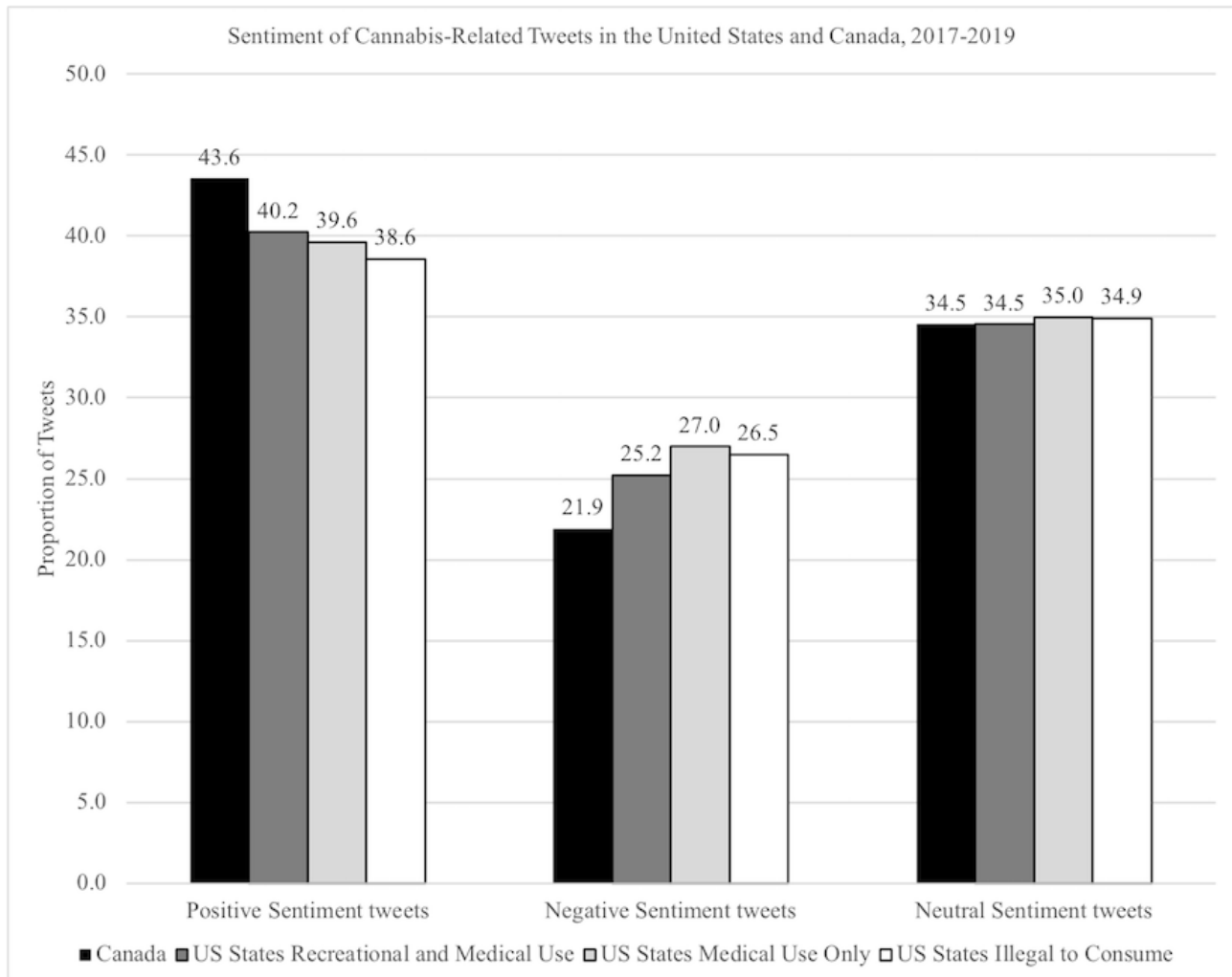
analyses were conducted separately for the US and Canada data sets. It is possible that a single tweet can contain multiple topics.

Results

Overall, most tweets were of positive sentiment (39.39% [472,746/1,200,127]) and proportions of neutral (34.50% [414,006/1,200,127]) and negative sentiment tweets were lower (26.11% [313,357/1,200,127]) in all data sets. Examples of tweets that were recorded in the positive sentiment category include “I love being from the Westside. Cooler weather and

better Weed,” and “Weed is just so great. And food is so great. And music is great. You’re all great. Everything’s great lol.” While negative sentiment tweets included, for example, “I hate the smell of weed. Hate it. Hate it. Hate it. Hate it. Hate it. Hate it. Hate it. Hate it. Hate it. Hate it. Hate it. Ha...” and “The marijuana prohibition has created more crime than alcohol prohibition did and is a bad idea.” Neutral sentiment tweets included, for example, “who would wanna smoke more weed to get less out of it...” and “Smoke this blunt then I’m sleep.” [Figure 1](#) depicts the proportion of positive, negative, and neutral sentiment tweets in Canada and the United States.

Figure 1. Sentiment of Cannabis-Related Tweets in the United States and Canada, 2017-2019.



As can be seen in [Table 1](#), the Canadian data set had a higher proportion of positive sentiment tweets than the United States data set overall (43.56% [22,210/37,050,924] vs 39.62% [325,699/587,058,027]; $P=.003$) and a lower proportion of negative tweets (21.90% [11,169/37,050,924] vs 26.99% [221,876/587,058,027]; $P=.001$). Differences are apparent in the proportion of negative sentiment tweets from states with adult recreational and medical, medical use only, and no legal

cannabis use policies ([Table 1](#)). The proportion of negative tweets was lower in states where adult recreational use was legal (25.22% [56,601/143,784,107]) than states where cannabis is illegal to consume (26.50% [23,711/98,092,868]; $P<.001$). States with more restrictive laws regarding cannabis use also had a smaller proportion of tweets that were cannabis related. See [Table 1](#) for a summary of the sentiment analysis. See [Multimedia Appendix 1](#) for full data analysis.

Table 1. Sentiment of cannabis-related tweets in the United States and Canada, January 2017-2019.

Tweet sentiment	Canada (N=37,050,924), n (%)	Pairwise comparison, P-values	US States Recreational and medical Use (1) (N=143,784,107), n (%)	US States Medical Use only (2) (N=587,058,027), n (%)	US States Illegal to consume (3) (N=98,092,868), n (%)	Pairwise comparison, P-values (Tukey adjusted)
Cannabis-related tweets	50,990 (0.14)	Canada vs United States: .375	224,462 (0.16)	821,970 (0.14)	89,482 (0.09)	1 vs 2: <.001 ^a 2 vs 3: <.001 ^a 1 vs 3: <.001 ^a
Positive sentiment tweets	22,210 (43.56)	Canada vs United States: .003 ^a	90,331 (40.24)	325,699 (39.62)	34,524 (38.58)	1 vs 2: .630 2 vs 3: .367 1 vs 3: .151
Negative sentiment tweets	11,169 (21.90)	Canada vs United States: .001 ^a	56,601 (25.22)	221,876 (26.99)	23,711 (26.50)	1 vs 2: .596 2 vs 3: <.001 ^a 1 vs 3: <.001 ^a
Neutral sentiment tweets	17,611 (34.54)	Canada vs United States: .887	77,530 (34.54)	287,618 (34.99)	31,247 (34.92)	1 vs 2: >.99 2 vs 3: .218 1 vs 3: .320

^aStatistical significance at the .05 level of significance.

Content analysis was done separately for tweets from the United States and Canada, to allow for detection of country-specific themes. In the US data set, Topic 1 contained tweets about the author having fun and getting high. Example tweets include “I’m glad we’ve gotten closer over the last year, I love smoking pot and talking shit with you in between shows” and “I love just smoking a blunt with nick and we can talk about anything.” Topic 2 was similar but distinct and contained tweets about living life and smoking cannabis and frequently included words such as smoke, people, make, today, live, start, day, and happy. Example tweets from Topic 2 include “Keep your head high and your joint higher” and “I live in Colorado and I’m artsy so I have like...an ounce of weed in my bag.” Topic 3 contained tweets related to transactions and also contained a racial slur as a keyword that came up frequently in posts that fell into this category. Example tweets include “Need to go buy bud to knock the fuck out,” and “You know the struggle when you can’t decide whether to spend money on weed or make up.” Topic 4 related to the places that people use cannabis and the associated scent. Example tweets include “My car doesn’t smell like pot anymore,” and “That moment when your dad follows you into your room and smells something funky but does realize it’s just weed.” Topic 5 contained tweets related to medical use and the cannabis industry with keywords such as medical, grow, business, industry, dispensary, company, health, and medicine. Example tweets include “What are your thoughts on the medical marijuana business (or recreational)? Worth investing?” and “If you’re looking for work in a growth industry, marijuana is booming.” Lastly, Topic 6 was about legalization and criminalization. Example tweets include “As CA business we

fought to end civil rights disaster of arresting marijuana users. Will your medical cannabis policy be guided by science or disproven statements?” and “For so long government wanted to criminalize marijuana but now they’re just trying to make sure they’re on the winnif end of legalization.” See [Table 2](#) for a list of the topic areas in the US data set and their frequency by state legal grouping.

Content analysis was also performed on the Canadian data set and similar topics were found with some slight differences ([Table 3](#)). Notably, themes related to everyday life and fun/recreation were present in a single topic area in the Canadian data set. Example tweets include “The summer will be well deserved. I plan on being intoxicated by alcohol or cannabis 90% of the time” and “As I wake n bake I’d like to acknowledge Mary Marijuana who has been amazing to me over many decades.” Topics related to medical use and the cannabis industry were 2 distinct themes. Example medical use tweets include “Fibromyalgia Targeted in AP-CBD/THC Therapy Now Undergoing Phase 1 Clinical Trial” and “Canada’s largest pharmacy chain says its own employees would be covered for medical marijuana prescriptions.” Example cannabis industry tweets include “Canadian cannabis industry raises \$700M in six months” and “Recalls force medical marijuana industry to step up quality testing threatening the pot industry to enforce federal laws to ban growing and selling marijuana.” The Canadian tweets contained frequent references to geographic places including cities and provinces. Finally, the Canadian data set contained minimal racial slurs in the topic about personal transactions, even after we tested specifically for the presence of this clustering of words.

Table 2. Topics in cannabis-related tweets by state legal category groupings, United States, January 2017-2019.

Topics	Theme keywords	Proportion of tweets in Theme ^a			
		US States Recreational and medical use % (N=224,462) ^b	US States Medical use only % (N=821,970) ^b	US States Il-legal to consume % (N=89,482) ^b	Overall % (N=1,135,914) ^b
1. Fun and recreation	Smoke, weed, blunt, fuck, lol people, love, life, day, high	26.25	31.24	33.20	30.21
2. Daily life	Weed, smoke, people, make, today, live, pot, start, day, happy	24.07	24.21	23.64	24.00
3. Transactions	Weed, buy, money, sell, shop, spend, store, make, deal, [racial slur]	11.52	11.77	13.00	12.13
4. Places of use	Weed, smell, car, smoke, room, mom, walk, house, marijuana, straight	11.81	12.31	12.53	12.23
5. Medical use/Cannabis industry	Marijuana, cannabis, medical, grow, business, industry, dispensary, company, health, medicine	16.01	9.90	7.31	10.99
6. Legalization	Marijuana, legal, legalize, state, cannabis, illegal, police, tax, legalization, arrest	10.34	10.56	10.32	10.44

^aThere are no n values supplied for the content analysis as tweets may have multiple topics.

^bThe N value corresponds to total cannabis-related tweets.

Table 3. Topics found in content analysis for cannabis-related tweets by state legal category groupings, Canada, January 2017-2019 (N=50,990).

Topics	Theme keywords	Proportion of tweets in theme, % ^a
1. Everyday life, Fun, Recreational use	Weed, smoke, people, day, today, fuck, high, love, alcohol, start	12.60
2. Cannabis industry	Cannabis, grow, marijuana, industry, market, company, sales, business, book, support	27.33
3. Transactions	Weed, sell, buy, marijuana, store, cannabis, Canada, order, money, Ontario	9.06
4. Places of use	Weed, smell, marijuana, smoke, time, make, Toronto, bad, walk, call	24.84
5. Medical use	Cannabis, medical, marijuana, health, dispensary, tax, dispensaries, medicine, pharma	6.68
6. Legalization	Marijuana, cannabis, legal, legalize, legalization, Canada, cdnpoli, police, justintrudeau, government	19.49

^aThere are no n values supplied for the content analysis as tweets may have multiple topics.

Discussion

Summary of Findings

Our study presents novel findings from a recent sentiment and content analysis of Twitter data, and is the first study to compare trends in online discussions about cannabis in Canada and the United States. Our analysis of cannabis-related tweets from January 2017 to 2019 found differences in the sentiment and content of tweets from states with adult recreational, medical, and no legal cannabis use policies, and Canada. States with more restrictive laws regarding cannabis use had both a smaller proportion of tweets that were cannabis-related and a higher proportion of tweets that had a negative sentiment than those with less restrictive laws. The US tweets overall contained a higher proportion of negative tweets and a lower proportion of positive tweets than tweets from Canada. This may be indicative of changes in public opinion, becoming more positive after legalization of cannabis, or it may simply be that people are

more comfortable sharing positive opinions and emotions in public, online forums when there are no potential legal ramifications for their actions.

The content analysis done on the US data set revealed some similar themes to previous content analyses such as current use and legalization, transactions, medical use, and the cannabis industry [13,24]; however, our analysis also presented new themes not uncovered in previous content analyses including the topics about the scent of cannabis and places that people use, and medical use and the cannabis industry. Our analysis did not detect several of the themes that other authors did, such as romance, tobacco, and friendship [15] or processed product use, cannabidiol and hemp use, and polysubstance use [24]. This could be because previous content analyses were conducted primarily with influential Twitter users, with adolescent users, and not with all available tweets [12,13,15,23] or because of a more expansive time frame and fewer geographic restrictions than other studies [24].

In the United States, tweets in Topic 5 (medical use and the cannabis industry) appear to be more common in states that have legalized cannabis for adult recreational use, possibly because these states have regulated environments for purchase and consumption of cannabis, and Twitter users in these places have more interaction with the cannabis industry. Similarly, Topic 3 (personal transactions) was more frequently found coming from Twitter users in states where all cannabis use was illegal, likely stemming from the need to buy and sell cannabis in an underground market, consisting of individual transactions.

In the Canadian data set, similar topics were found with some slight differences. Topics related to medical use and the cannabis industry were 2 distinct themes in Canada, likely because adult recreational use was legalized in the study period and the regulatory environment separated medical and adult recreational use (both being or becoming legal, but sold and regulated in different ways).

Legalization was also discussed differently in the 2 data sets. The Canadian discussions of legalization were more politicized with terms such as *justinrudeau* and *canpoli* coming up frequently, whereas the US legalization theme included the words *police* and *arrest*. These differences may reflect cannabis legalization being a national political issue in Canada, as it was tied to party platforms in the 2015 federal election cycle and became a major campaign promise of the Liberal government. These differences may also reflect the persistent enforcement of low-level drug offences in the United States and the relatively high levels of incarceration associated with cannabis in the United States (making up 40%-50% of drug charges) [29].

Other differences between the themes within the Canadian and US data sets include the frequency of the presence of the word *cannabis* in the Canadian tweets. This is the term preferred by the Canadian government, and evidently has spread into personal communications. In the US data set, slang words for cannabis were more frequently present including *weed* and *pot* and *blunt*, possibly because of the absence of discussions that use more formal language in national policy spaces permeating into personal communications, or possibly because of differences in who is tweeting about cannabis. The word *marijuana* was frequently present in both data sets. In the Canadian data set, alcohol is included as a keyword in Topic 1, which is about recreational use, a term not found in the US clusters.

Finally, the Canadian data set contained fewer racial slurs in the topic about personal transactions, even after we tested specifically for the presence of this clustering of words. It may represent a troubling normalization of derogatory language toward African Americans in the United States, or it may be representing larger, structural issues in the racialization of drug enforcement [29,35] and perceptions of who is selling drugs. Although the proportion of White Americans who consume marijuana has repeatedly been reported to be either similar to or higher than the proportion of Black Americans, there are differences in racialized perceptions of use and racialized drug enforcement [29,35]. Alternately, it could represent an increase in online conversations about cannabis among minorities in the United States, which has also been documented in other studies [15].

Limitations

Our analysis was limited to tweets with location data, English language content, and those from United States and Canada, limiting the generalizability of the findings. Further, studies have shown that there can be bias related to population demographics at the state and city level [36] as well as temporal and spatial factors at the individual level [37] that can affect the sentiment of tweets. Geotagged Twitter data are a subset of general Twitter data and may not accurately represent the wider population. For example, only 15% of adults who use the internet use Twitter with regularity, and those aged 18-29 as well as minorities tend to be more highly represented on Twitter than in the general population. There are higher proportions of both passive users (<50 tweets per year) and highly active users (>1000 tweets per year) than moderate users (50-1000 tweets per year) on Twitter [38]. Taken together, these limitations indicate that the data used in this study are from nonuniformly gathered statements from a nonrepresentative subset of the US and Canadian populations.

The analytic methods used to ascertain sentiment was based on the tone of words used in the tweets, and thus a tweet's sentiment does not necessarily reflect the Twitter user's stance on cannabis usage and does not translate to procannabis or anticannabis opinion. In stance detection, the analysis needs to determine favorability toward a given target of interest. The target of interest is often prechosen and may not be explicitly mentioned in the text and it may not be the target of opinion in the text [39]. Other scholars have performed sentiment analyses on cannabis-related tweets using different methods and restricting analysis to Twitter users having high Klout scores, finding closer to 65%-77% of tweets with a positive sentiment [13]. We expect the higher proportions of positive sentiment in the previously referenced paper are due to selecting users with a high Klout score, who have more positive sentiment overall than lower Klout score users, as well as their use of a custom classification method designed to capture the intent of the tweet rather than just the sentiment [13]. We manually classified 350 tweets ourselves based on emotional tone and compared these with VADER Sentiment and found that VADER was nearly 85% accurate with only 51 misclassified out of 350 (14.6%), giving us confidence in the sentiment results presented here.

Further methodological limitations include that we are not able to filter out bots from the data set, although we have removed duplicate tweets. Data from the 3 US states included that had cannabis law changes during the study period may not fully represent cannabis tweet sentiment in these states, and study results should not be generalized beyond the limited time frame in which data were collected. Finally, we were not able to retrieve tweets from accounts which were marked as private by the API.

Public Health Implications

We document a notable difference in the sentiment of tweets whereby less restrictive policy environments appear to be associated with less negative sentiment in tweets and perceptible differences in Twitter content between the United States and Canada. The implications of this work extend beyond just online messaging. Cannabis is the most commonly used drug in both

the United States and Canada, with between 13% and 18% of the general population reporting recent use [37,40]. Cannabis use and cannabis use disorder are significantly associated with higher levels of exposure to procannabis content on Twitter [12] and living in places with more liberal cannabis policies [37,41], suggesting that such exposures are consequential.

Other studies have documented the procannabis sentiment of much of the cannabis-related Tweets from the general public [12], and this taken in tandem with the documented lack of cannabis-related educational information on Twitter from health organizations [42] suggests that Twitter users (especially in states with less restrictive policy environments) may benefit from information regarding how to use cannabis in ways that minimize health-related harms. Some examples of educational messages designed to target adults in the general public and to help maximize safety and health when using cannabis include

“start low and go slow” as well as “use cannabis in a safe and familiar environment with people you trust” and “if you are a new consumer, look for a product with less than 100 mg/g (10%) THC, with equal or higher levels of CBD,” etc [37].

Knowledge generated in this study about how cannabis is being discussed online, and geographic differences that exist in these conversations may help to inform public health planning and prevention efforts. For example, campaigns targeting specific geographic areas may be useful as cannabis laws become less restrictive in the United States. The content analysis conducted in this study highlighted some potential trends that deserve further investigation. Future research is needed on the racialized nature of cannabis conversations on Twitter, the potential role of social media in buying and selling cannabis, and emerging trends surrounding places of use (eg, use at home, use in public spaces).

Conflicts of Interest

None declared.

Multimedia Appendix 1

Data analysis script and data file.

[\[DOCX File , 16 KB - publichealth_v6i4e18540_app1.docx \]](#)

References

1. Eysenbach G. Infodemiology and infoveillance tracking online health information and cyberbehavior for public health. *Am J Prev Med* 2011;40(5):S154-S158 [FREE Full text]
2. Liu S, Young SD. A survey of social media data analysis for physical activity surveillance. *Journal of Forensic and Legal Medicine* 2018 Jul;57:33-36. [doi: [10.1016/j.jflm.2016.10.019](https://doi.org/10.1016/j.jflm.2016.10.019)] [Medline: [29801949](https://pubmed.ncbi.nlm.nih.gov/29801949/)]
3. Gilbert C, Hutto E. Vader: A parsimonious rule-based model for sentiment analysis of social media text. 2014 Presented at: Eighth International Conference on Weblogs Social Media (ICWSM-14); 2014; Ann Arbor, MI URL: <http://comp.social.gatech.edu/papers/icwsm14.vader.hutto.pdf> [doi: [10.18574/nyu/9780814708453.003.0004](https://doi.org/10.18574/nyu/9780814708453.003.0004)]
4. Mimno D, Wallach H, Talley E, Leenders M, McCallum A. Optimizing semantic coherence in topic models. 2011 Presented at: Proceedings of the 2011 Conference on Empirical Methods in Natural Language Processing; 2011; Edinburgh, Scotland, UK p. 262-272 URL: <http://dirichlet.net/pdf/mimno11optimizing.pdf>
5. O'Callaghan D, Greene D, Carthy J, Cunningham P. An analysis of the coherence of descriptors in topic modeling. *Expert Systems with Applications* 2015 Aug;42(13):5645-5657. [doi: [10.1016/j.eswa.2015.02.055](https://doi.org/10.1016/j.eswa.2015.02.055)]
6. De Choudhury M, Gamon M, Counts S, Horvitz E. Predicting depression via social media. 2013 Presented at: International AAAI Conference on Weblogs and Social Media (ICWSM-13); July 8–11, 2013; Cambridge, Massachusetts, USA p. 128-137 URL: <https://www.aaai.org/ocs/index.php/ICWSM/ICWSM13/paper/viewFile/6124/6351>
7. Liu S, Zhu M, Yu DJ, Rasin A, Young SD. Using Real-Time Social Media Technologies to Monitor Levels of Perceived Stress and Emotional State in College Students: A Web-Based Questionnaire Study. *JMIR Ment Health* 2017 Jan 10;4(1):e2 [FREE Full text] [doi: [10.2196/mental.5626](https://doi.org/10.2196/mental.5626)] [Medline: [28073737](https://pubmed.ncbi.nlm.nih.gov/28073737/)]
8. Chew C, Eysenbach G. Pandemics in the age of Twitter: content analysis of Tweets during the 2009 H1N1 outbreak. *PLoS One* 2010;5(11):e14118 [FREE Full text] [doi: [10.1371/journal.pone.0014118](https://doi.org/10.1371/journal.pone.0014118)] [Medline: [21124761](https://pubmed.ncbi.nlm.nih.gov/21124761/)]
9. Liu S, Chen B, Kuo A. Monitoring Physical Activity Levels Using Twitter Data: Infodemiology Study. *J Med Internet Res* 2019 Jun 03;21(6):e12394 [FREE Full text] [doi: [10.2196/12394](https://doi.org/10.2196/12394)] [Medline: [31162126](https://pubmed.ncbi.nlm.nih.gov/31162126/)]
10. Hanson CL, Burton SH, Giraud-Carrier C, West JH, Barnes MD, Hansen B. Tweaking and tweeting: exploring Twitter for nonmedical use of a psychostimulant drug (Adderall) among college students. *J Med Internet Res* 2013 Apr 17;15(4):e62 [FREE Full text] [doi: [10.2196/jmir.2503](https://doi.org/10.2196/jmir.2503)] [Medline: [23594933](https://pubmed.ncbi.nlm.nih.gov/23594933/)]
11. West JH, Hall PC, Hanson CL, Prier K, Giraud-Carrier C, Neeley ES, et al. Temporal variability of problem drinking on Twitter. *OJPM* 2012;02(01):43-48. [doi: [10.4236/ojpm.2012.21007](https://doi.org/10.4236/ojpm.2012.21007)]
12. Cabrera-Nguyen EP, Cavazos-Rehg P, Krauss M, Bierut LJ, Moreno MA. Young Adults' Exposure to Alcohol- and Marijuana-Related Content on Twitter. *J Stud Alcohol Drugs* 2016 Mar;77(2):349-353 [FREE Full text] [doi: [10.15288/jsad.2016.77.349](https://doi.org/10.15288/jsad.2016.77.349)] [Medline: [26997194](https://pubmed.ncbi.nlm.nih.gov/26997194/)]

13. Cavazos-Rehg P, Krauss M, Gruzca R, Bierut L. Characterizing the followers and tweets of a marijuana-focused Twitter handle. *J Med Internet Res* 2014 Jun 27;16(6):e157 [FREE Full text] [doi: [10.2196/jmir.3247](https://doi.org/10.2196/jmir.3247)] [Medline: [24974893](https://pubmed.ncbi.nlm.nih.gov/24974893/)]
14. Daniulaityte R, Nahhas R, Wijeratne S, Carlson R, Lamy F, Martins S, et al. Time for dabs?: Analyzing Twitter data on marijuana concentrates across the US. *Drug Alcohol Depend* 2015 Oct 01;155:307-311 [FREE Full text] [doi: [10.1016/j.drugalcdep.2015.07.1199](https://doi.org/10.1016/j.drugalcdep.2015.07.1199)] [Medline: [26338481](https://pubmed.ncbi.nlm.nih.gov/26338481/)]
15. Cavazos-Rehg PA, Krauss M, Fisher SL, Salyer P, Gruzca RA, Bierut LJ. Twitter chatter about marijuana. *J Adolesc Health* 2015 Feb;56(2):139-145 [FREE Full text] [doi: [10.1016/j.jadohealth.2014.10.270](https://doi.org/10.1016/j.jadohealth.2014.10.270)] [Medline: [25620299](https://pubmed.ncbi.nlm.nih.gov/25620299/)]
16. Lamy FR, Daniulaityte R, Sheth A, Nahhas RW, Martins SS, Boyer EW, et al. "Those edibles hit hard": Exploration of Twitter data on cannabis edibles in the U.S. *Drug Alcohol Depend* 2016 Jul 01;164:64-70 [FREE Full text] [doi: [10.1016/j.drugalcdep.2016.04.029](https://doi.org/10.1016/j.drugalcdep.2016.04.029)] [Medline: [27185160](https://pubmed.ncbi.nlm.nih.gov/27185160/)]
17. Daniulaityte R, Chen L, Lamy F, Carlson R, Thirunarayan K, Sheth A. "When 'Bad' is 'Good'": Identifying Personal Communication and Sentiment in Drug-Related Tweets. *JMIR Public Health Surveill* 2016 Oct 24;2(2):e162 [FREE Full text] [doi: [10.2196/publichealth.6327](https://doi.org/10.2196/publichealth.6327)] [Medline: [27777215](https://pubmed.ncbi.nlm.nih.gov/27777215/)]
18. Government of Canada. Justice laws website [Internet]. Cannabis Act. 2018. URL: <https://laws-lois.justice.gc.ca/eng/acts/C-24.5/> [accessed 2019-07-27]
19. National Conference of State Legislators. State medical marijuana laws website [Internet]. 2019. URL: <http://www.ncsl.org/research/health/state-medical-marijuana-laws.aspx#2> [accessed 2019-06-25]
20. Daniulaityte R, Lamy F, Smith G, Nahhas R, Carlson R, Thirunarayan K, et al. Retweet to pass the blunt?: Analyzing geographic and content features of cannabis-related tweeting across the United States. *J Stud Alcohol Drugs* 2017 Nov;78(6):910-915 [FREE Full text] [doi: [10.15288/jsad.2017.78.910](https://doi.org/10.15288/jsad.2017.78.910)] [Medline: [29087826](https://pubmed.ncbi.nlm.nih.gov/29087826/)]
21. Meng H, Kath S, Li D, Nguyen QC. National substance use patterns on Twitter. *PLoS One* 2017 Nov 6;12(11):e0187691 [FREE Full text] [doi: [10.1371/journal.pone.0187691](https://doi.org/10.1371/journal.pone.0187691)] [Medline: [29107961](https://pubmed.ncbi.nlm.nih.gov/29107961/)]
22. Lamy FR, Daniulaityte R, Zatreh M, Nahhas RW, Sheth A, Martins SS, et al. You got to love rosin: solventless dabs, pure, clean, natural medicine.? Exploring Twitter data on emerging trends in Rosin Tech marijuana concentrates. *Drug Alcohol Depend* 2018 Feb 01;183:248-252 [FREE Full text] [doi: [10.1016/j.drugalcdep.2017.10.039](https://doi.org/10.1016/j.drugalcdep.2017.10.039)] [Medline: [29306816](https://pubmed.ncbi.nlm.nih.gov/29306816/)]
23. Krauss M, Gruzca R, Bierut L, Cavazos-Rehg P. "Get drunk. Smoke weed. Have fun.": A Content Analysis of Tweets About Marijuana and Alcohol. *Am J Health Promot* 2016 Nov 17;31(3):200-208. [doi: [10.4278/ajhp.150205-qual-708](https://doi.org/10.4278/ajhp.150205-qual-708)]
24. Allem J, Escobedo P, Dharmapuri L. Cannabis Surveillance With Twitter Data: Emerging Topics and Social Bots. *Am J Public Health* 2020 Mar;110(3):357-362. [doi: [10.2105/ajph.2019.305461](https://doi.org/10.2105/ajph.2019.305461)]
25. Twitter. Filter realtime Tweets [Internet]. 2017. URL: <https://developer.twitter.com/en/docs/twitter-api/v1/tweets/filter-realtime/overview> [accessed 2020-05-20]
26. State Policy: Marijuana Policy Project [Internet]. 2019. URL: <https://www.mpp.org/states/> [accessed 2019-10-16]
27. Thompson L, Rivara F, Whitehill J. Prevalence of Marijuana-Related Traffic on Twitter, 2012-2013: A Content Analysis. *Cyberpsychol Behav Soc Netw* 2015 Jun;18(6):311-319 [FREE Full text] [doi: [10.1089/cyber.2014.0620](https://doi.org/10.1089/cyber.2014.0620)] [Medline: [26075917](https://pubmed.ncbi.nlm.nih.gov/26075917/)]
28. Vader Sentiment. GitHub. URL: <https://github.com/cjhutto/vaderSentiment> [accessed 2020-08-05]
29. Sentiment Analysis Code. GitHub. URL: https://github.com/SakshamGupta55/NLP-on-tweets-from-social-media/blob/master/code_Sentiment_Analysis.py%0D%0A%0D%0A [accessed 2020-08-05]
30. Jaccard J, Becker M, Wood G. Pairwise multiple comparison procedures: A review. *Psychological Bulletin* 1984;96(3):589-596. [doi: [10.1037/0033-2909.96.3.589](https://doi.org/10.1037/0033-2909.96.3.589)]
31. Guo Y, Barnes S, Jia Q. Mining meaning from online ratings and reviews: Tourist satisfaction analysis using latent dirichlet allocation. *Tourism Management* 2017 Apr;59:467-483. [doi: [10.1016/j.tourman.2016.09.009](https://doi.org/10.1016/j.tourman.2016.09.009)]
32. Blei D, Ng A, Jordan M. Latent dirichlet allocation. *J Mach Learn Res* 2003;3:993-1022 [FREE Full text]
33. Chang J, Gerrish S, Wang C, Boyd-Graber JL, Blei DM. Reading tea leaves: How humans interpret topic models. *Neural Information Processing Systems*. 2009. URL: <https://papers.nips.cc/paper/3700-reading-tea-leaves-how-humans-interpret-topic-models.pdf> [accessed 2020-09-23]
34. Steinskog A, Therkelsen J, Gambäck B. Twitter topic modeling by tweet aggregation. 2017 Presented at: Proceedings of the 21st Nordic Conference on Computational Linguistics; 2017; Gothenburg, Sweden p. 77-86 URL: <https://www.aclweb.org/anthology/W17-0210.pdf>
35. Bender S. The Colors of Cannabis: Race and Marijuana. 2016. URL: <https://digitalcommons.law.seattleu.edu/faculty/778> [accessed 2020-05-20]
36. Gore RJ, Diallo S, Padilla J. You Are What You Tweet: Connecting the Geographic Variation in America's Obesity Rate to Twitter Content. *PLoS One* 2015;10(9):e0133505 [FREE Full text] [doi: [10.1371/journal.pone.0133505](https://doi.org/10.1371/journal.pone.0133505)] [Medline: [26332588](https://pubmed.ncbi.nlm.nih.gov/26332588/)]
37. Padilla JJ, Kavak H, Lynch CJ, Gore RJ, Diallo SY. Temporal and spatiotemporal investigation of tourist attraction visit sentiment on Twitter. *PLoS One* 2018 Jun 14;13(6):e0198857 [FREE Full text] [doi: [10.1371/journal.pone.0198857](https://doi.org/10.1371/journal.pone.0198857)] [Medline: [29902270](https://pubmed.ncbi.nlm.nih.gov/29902270/)]
38. Smith A, Brenner J. Twitter Use 2012. Washington, DC: Pew Research Center; 2012. URL: <https://www.pewresearch.org/internet/2012/05/31/twitter-use-2012/> [accessed 2020-05-20]

39. Sobhani P, Mohammad S, Kiritchenko S. Detecting stance in tweets and analyzing its interaction with sentiment. 2016 Presented at: Proceedings of the Fifth Joint Conference on Lexical and Computational Semantics (*SEM 2016); August 11-12, 2016; Berlin, Germany p. 159-169 URL: <https://www.aclweb.org/anthology/S16-2021.pdf> [doi: [10.18653/v1/s16-2021](https://doi.org/10.18653/v1/s16-2021)]
40. Daniulaityte R, Zatreh MY, Lamy FR, Nahhas RW, Martins SS, Sheth A, et al. A Twitter-based survey on marijuana concentrate use. *Drug Alcohol Depend* 2018 Jun 01;187:155-159 [FREE Full text] [doi: [10.1016/j.drugalcdep.2018.02.033](https://doi.org/10.1016/j.drugalcdep.2018.02.033)] [Medline: [29669296](https://pubmed.ncbi.nlm.nih.gov/29669296/)]
41. Cerdá M, Wall M, Keyes K, Galea S, Hasin D. Medical marijuana laws in 50 states: investigating the relationship between state legalization of medical marijuana and marijuana use, abuse and dependence. *Drug Alcohol Depend* 2012 Jan 01;120(1-3):22-27 [FREE Full text] [doi: [10.1016/j.drugalcdep.2011.06.011](https://doi.org/10.1016/j.drugalcdep.2011.06.011)] [Medline: [22099393](https://pubmed.ncbi.nlm.nih.gov/22099393/)]
42. van Draanen J, Krishna T, Tsang C, Liu S. Keeping up with the times: how national public health and governmental organizations communicate about cannabis on Twitter. *Subst Abuse Treat Prev Policy* 2019 Sep 12;14(1):38 [FREE Full text] [doi: [10.1186/s13011-019-0224-3](https://doi.org/10.1186/s13011-019-0224-3)] [Medline: [31511026](https://pubmed.ncbi.nlm.nih.gov/31511026/)]

Abbreviations

- API:** application programming interface
CBD: cannabidiol
LDA: latent Dirichlet allocation
THC: tetrahydrocannabinol
VADER: Valence Aware Dictionary and sEntiment Reasoner

Edited by T Sanchez; submitted 19.03.20; peer-reviewed by R Gore, A Dormanesh, JP Allem, K McCausland; comments to author 15.06.20; revised version received 28.08.20; accepted 31.08.20; published 05.10.20.

Please cite as:

van Draanen J, Tao H, Gupta S, Liu S
Geographic Differences in Cannabis Conversations on Twitter: Infodemiology Study
JMIR Public Health Surveill 2020;6(4):e18540
URL: <https://publichealth.jmir.org/2020/4/e18540>
doi: [10.2196/18540](https://doi.org/10.2196/18540)
PMID: [33016888](https://pubmed.ncbi.nlm.nih.gov/33016888/)

©Jenna van Draanen, HaoDong Tao, Saksham Gupta, Sam Liu. Originally published in JMIR Public Health and Surveillance (<http://publichealth.jmir.org>), 05.10.2020. This is an open-access article distributed under the terms of the Creative Commons Attribution License (<https://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in JMIR Public Health and Surveillance, is properly cited. The complete bibliographic information, a link to the original publication on <http://publichealth.jmir.org>, as well as this copyright and license information must be included.

Original Paper

E-Cigarette Promotion on Twitter in Australia: Content Analysis of Tweets

Kahlia McCausland¹, BSc; Bruce Maycock², PhD; Tama Leaver³, PhD; Katharina Wolf⁴, PhD; Becky Freeman⁵, PhD; Katie Thomson⁶, BSc; Jonine Jancey¹, PhD

¹Collaboration for Evidence, Research and Impact in Public Health, School of Public Health, Curtin University, Bentley, Australia

²College of Medicine and Health, University of Exeter, Devon, United Kingdom

³School of Media, Creative Arts and Social Inquiry, Curtin University, Bentley, Australia

⁴School of Marketing, Curtin University, Bentley, Australia

⁵School of Public Health, University of Sydney, Sydney, Australia

⁶School of Public Health, Curtin University, Bentley, Australia

Corresponding Author:

Kahlia McCausland, BSc

Collaboration for Evidence, Research and Impact in Public Health

School of Public Health

Curtin University

Kent Street

Bentley, 6102

Australia

Phone: 61 92667382

Email: kahlia.mccausland@curtin.edu.au

Abstract

Background: The sale of electronic cigarettes (e-cigarettes) containing nicotine is prohibited in all Australian states and territories; yet, the growing availability and convenience of the internet enable the promotion and exposure of e-cigarettes across countries. Social media's increasing pervasiveness has provided a powerful avenue to market products and influence social norms and risk behaviors. At present, there is no evidence of how e-cigarettes and vaping are promoted on social media in Australia.

Objective: This study aimed to investigate how e-cigarettes are portrayed and promoted on Twitter through a content analysis of vaping-related tweets containing an image posted and retweeted by Australian users and how the portrayal and promotion have emerged and trended over time.

Methods: In total, we analyzed 1303 tweets and accompanying images from 2012, 2014, 2016, and 2018 collected through the Tracking Infrastructure for Social Media Analysis (TrISMA), a contemporary technical and organizational infrastructure for the tracking of public communication by Australian users of social media, via a list of 15 popular e-cigarette-related terms.

Results: Despite Australia's cautious approach toward e-cigarettes and the limited evidence supporting them as an efficacious smoking cessation aid, it is evident that there is a concerted effort by some Twitter users to promote these devices as a health-conducive (91/129, 70.5%), smoking cessation product (266/1303, 20.41%). Further, Twitter is being used in an attempt to circumvent Australian regulation and advocate for a more liberal approach to personal vaporizers (90/1303, 6.90%). A sizeable proportion of posts was dedicated to selling or promoting vape products (347/1303, 26.63%), and 19.95% (260/1303) were found to be business listings. These posts used methods to try and expand their clientele further than immediate followers by touting competitions and giveaways, with those wanting to enter having to perform a sequence of steps such as liking, tagging, and reposting, ultimately exposing the post among the user's network and to others not necessarily interested in vaping.

Conclusions: The borderless nature of social media presents a clear challenge for enforcing Article 13 of the World Health Organization Framework Convention on Tobacco Control, which requires all ratifying nations to implement a ban on tobacco advertising, promotion, and sponsorship. Countering the advertising and promotion of these products is a public health challenge that will require cross-border cooperation with other World Health Organization Framework Convention on Tobacco Control parties. Further research aimed at developing strategies to counter the advertising and promotion of e-cigarettes is therefore needed.

KEYWORDS

electronic cigarette; e-cigarette; electronic nicotine delivery systems; vaping; vape; social media; twitter; content analysis; public health; public policy

Introduction

In Australia, the context of the present study, the legal status of electronic cigarettes (e-cigarettes) is determined by existing and overlapping laws relating to poisons, therapeutic and consumer goods, and tobacco control [1]. Liquid nicotine is classified as a “Schedule 7-Dangerous Poison” under the Federal Poisons Standard [2], and, as such, the manufacture, sale, or supply of e-cigarettes containing nicotine without lawful authority (ie, prescription from a medical doctor) [3] is prohibited in all Australian states and territories [4]. However, nicotine-containing e-cigarettes can be imported into Australia, as there is no way to determine whether or not an e-cigarette contains nicotine, short of laboratory analysis, which has implications for law enforcement [4,5]. E-cigarettes that do not contain nicotine can be sold in some Australian jurisdictions, provided manufacturers do not make therapeutic claims, while the sale and use of flavored e-liquid are permitted provided it does not contain nicotine [4].

The World Health Organization Framework Convention on Tobacco Control (WHO FCTC) defines tobacco advertising and promotion as “any form of commercial communication, recommendation or action with the aim, effect or likely effect of promoting a tobacco product or tobacco use either directly or indirectly” and requires signatories to the treaty, of which Australia is one, to “undertake a comprehensive ban on all tobacco advertising, promotion and sponsorship” [6]. As nicotine-containing e-cigarettes are banned from retail sale in Australia; the advertising of such products is also not permitted. Further, advertising of all types of e-cigarette products and devices, nonnicotine included, is regulated at the state level, with most states prohibiting any form of advertising or promotion [7-10].

Data from the most recent National Drug Strategy Household Survey [11] report 11.3% of Australians aged over 14 years have ever used, and 2.5% currently use, e-cigarettes, increasing from 8.8% and 1.2%, respectively, since 2016. These increases occurred in both smokers and nonsmokers and contrast with Australian combustible smoking rates, which have continued to decline over the last 30 years. The most frequent reason for using e-cigarettes reported by people older than 14 years was “out of curiosity” (54.2%). Further, 22.8% cited using e-cigarettes because they perceived them to be less harmful than tobacco cigarettes (19.2% in 2016), and 10.1% believed vaping to be more socially acceptable than tobacco smoking (6.0% in 2016). In addition, 26.9% of respondents reported they obtained their e-cigarette products online (Australian retailer 12.5%, overseas retailer 11.1%, unknown origin 3.3%).

Vaping has become increasingly popular, and awareness, experimentation, and uptake have proliferated both within Australia and globally [12]. Researchers have therefore begun

harnessing data from social media to address information gaps, provide timely insights, and inform public policy and public health [13-15]. As of January 2019, there were approximately 2.56 million active monthly Australian Twitter users (64% male), which equates to approximately 12% of Australians older than 13 years [16]. Given the popularity of Twitter [16], the high-speed nature of information dissemination, and the significant influence of Twitter as a driver of web traffic [17], insights into how Twitter is used to promote and discuss e-cigarettes are warranted.

Social media’s increasing pervasiveness has provided a powerful avenue to market products and influence social norms and behaviors [18]. There is mounting evidence of the volume of e-cigarette promotion on social media [19,20], with studies suggesting adolescents who view e-cigarette social media promotion express greater intention to use e-cigarettes, more positive attitudes toward e-cigarettes, and greater perceptions of e-cigarette use as normative [21,22]. This is concerning, as Australia’s current regulatory stance has proven effective in limiting e-cigarette uptake [11]; however, promotion on social media could bring awareness to and encourage experimentation with e-cigarettes or other tobacco products [23,24]. The health effects of e-cigarette use are not fully understood; however, a growing body of literature has established acute consequences with even short-term use, with [25] or without nicotine [26,27].

A 2019 scoping review [19] that aimed to identify and describe the messages presented in e-cigarette-related social media promotions and discussions across the United Kingdom, United States, New Zealand, Canada, and Australia identified no studies from Australia. At the time of this study, there was no published literature on how e-cigarettes are promoted and discussed online in the Australian context. We, therefore, aimed to investigate how e-cigarettes are portrayed and promoted on Twitter through a content analysis of related tweets posted and retweeted by Australian users and how the portrayal and promotion have trended over time in the Australian context where e-cigarettes are largely prohibited.

Methods

Data Collection

Twitter data were collected via Tracking Infrastructure for Social Media Analysis (TrISMA) [28], a contemporary technical and organizational infrastructure for the tracking of public communication by Australian users of social media. Central to the TrISMA Twitter infrastructure is the Australian Twitter Collection, which continuously gathers tweets from identified Australian accounts (ie, accounts set to an Australian location, geolocation, or time zone or accounts with a description field referring to an Australian location or containing Australia-specific terms) and stores them in a database available to accredited TrISMA researchers. The TrISMA Twitter

Collection is hosted on a cloud-based Google BigQuery database and accessed through the data visualization tool Tableau.

A list of popular e-cigarette-related terms was developed based on peer-reviewed literature [29-34], trending Twitter hashtags, and frequently co-occurring hashtags (ie, hashtags that appeared in the same caption as the root term), which resulted in 15 keywords: *cloudchasing*, *ecig* (includes ecigarette/s), *e-cig* (includes e-cigarette/s), *electroniccig* (includes electroniccigarette/s), *electronic cigarette* (includes electronic cigarettes), *eliquid*, *e-liquid*, *e-juice*, *vape* (includes vaper and vapes), *vaping*, *vapecommunity*, *vapfam*, *vapelife*, *vapenation*, and *vapeporn*. E-cigarette product names were omitted from the search strategy so as not to bias the results to specific brands [35]. A preliminary search revealed there was minimal Twitter activity using these keywords before 2012. Therefore, 2 yearly sampling intervals starting from 2012 to 2018 were chosen to maximize the period of time covered while still being able to see the emergence and decline of trends in the collected data.

Data (tweets), along with meta-data information (ie, username, user follower count), were collected from public Australian Twitter users when a tweet included at least one of the identified keywords from either respective year. Data were downloaded in the form of comma-separated values files for each keyword and respective year. Social media users tend to include multiple hashtags within their posts, which resulted in duplicate tweets being collected. Duplicate tweets within keyword corpora for each year and across keyword corpora from the co-use of hashtags were removed, resulting in the inclusion of only unique tweets [36].

Data were assigned a number in ascending order, and 100 tweets from each keyword corpus for each year were randomly selected using an online random sequence generator [37]. Selected data were checked by one researcher (KM) to determine eligibility (ie, written in English and relevant to e-cigarettes). If any of the originally selected 100 tweets did not fit the inclusion criteria, further sampling occurred until 100 eligible tweets were reached. If a keyword corpus had less than 100 tweets, then all eligible tweets were selected. Each tweet was inspected, and, if found to contain an image, a screenshot of the whole post (text and image) was saved for further analysis. Eligible images needed to be stationary (ie, not a video, animated graphic interchange format [GIF], or other moving content). Only posts that contained an image were included in this study as the influence of the “picture superiority effect,” which specifies pictures and images are more likely to be remembered than words, is widely acknowledged [38]. Social media content that includes associated imagery is also more noticeable, shareable, and engaging to users [39].

Retweets (tweets reposted by users) were included in this study, which facilitated the understanding of what information was being circulated by Australian users, even if it originated in another country.

Ethical Considerations

A particularly salient concern among researchers is whether social media data should be considered public or private data

[40]. Twitter is a social networking service in which users broadcast their opinions and commonly use a hashtag to associate their thoughts on a subject with users on the same subject; therefore, this data is generally referred to as “public data” [40]. For ethical, privacy, and technical reasons, TrISMA does not collect tweets from private accounts or direct messages; therefore, all data collected in this study were publicly available. This study was approved by the Curtin University Human Research Ethics Committee (approval number: HRE2017-0144).

Developing the Coding Framework

A concept-driven approach (inductive) [41] informed by extant studies [29-34] was utilized to develop a coding framework. The coding frame was tested on a random sample of 100 tweets by 2 researchers (KM and KT), whereby each tweet was read and assigned codes based upon the concepts presented in the descriptive text, hashtags, and accompanying image [42]. It is critical to consider the visual and textual aspects of posts together in the analysis [42] as the study of images can be used to complement and extend the study of health behaviors and may be more valuable than the study of words alone [15]. The 2 researchers followed a hybrid inductive/deductive content analysis approach [41] to refine and further develop the coding framework before transferring the modified framework into IBM SPSS Statistics (v22).

Interrater Reliability Testing

The 2 researchers applied the modified coding framework to a sample of 140 randomly selected posts (approximately 10% of the final sample), and an interrater reliability test was performed. Interrater reliability was determined using Krippendorff alpha, and an average score of $\alpha=.89$ was obtained, with a range of .65-1.0, indicating good to perfect agreement [43]. Any discrepancies were discussed to reach consensus, and the coding framework was revised accordingly.

Coding and Analysis

The final coding framework (Multimedia Appendix 1) was applied by KT and checked for consistency and validity by KM. The coders met regularly to refine coding rules and discuss questions and emergent themes. Each code within the coding framework was a variable in SPSS that functioned as a standalone item and was evaluated as either 1 for present or 2 for absent. Statistical comparisons (ie, between codes and years) were made using chi-square tests or Fisher exact tests, if applicable. Data were analyzed using IBM SPSS Statistics (v22). Due to the small sample size of the 2012 data, a further sensitivity analysis was performed with statistical comparisons made using chi-square and Fisher exact tests to assess the robustness of the results by removing the observations in 2012.

Results

Sample of Posts

Of the 4437 randomly selected tweets, 1553 contained an image, and an eligible sample of 1303 tweets was retained for analysis (Table 1).

Table 1. Number of posts selected for analysis.

Year of post	Random sample of posts (n=4437), n	Posts containing an image (n=1553), n	Posts eligible for analysis (n=1303), n
2012	570	12	12
2014	1,196	289	246
2016	1,378	658	540
2018	1,293	594	505

Sensitivity Analysis

After performing the sensitivity analysis, all associations, except for one, remained significant when removing the 12 observations from 2012. After the removal of the 2012 data, the “quit smoking” association did not retain its significance ($P=.213$). The results of the sensitivity analysis indicate that, overall, the results were not substantially influenced by the small number of data in 2012.

Frequency and Description of Codes

Overview

In total, 1303 tweets and accompanying images (collectively referred to as posts) were analyzed: 12 from 2012, 246 from 2014, 540 from 2016, and 505 from 2018.

People

Of the images that contained a person, 60.0% (326/543) portrayed a man, and the majority of people appeared to be over the age of 18 years (300/313, 95.8%; [Table 2](#)). The largest proportion of people visible in these images was classified as “everyday people” (283/543, 52.1%).

Table 2. Frequency statistics for each year corpus and the total sample within the “people” domain.

Associated codes	2012 (N=12), n (%)	2014 (N=246), n (%)	2016 (N=540), n (%)	2018 (N=505), n (%)	Total (N=1303), n (%)
People visible	4 (33.3)	115 (46.7)	209 (38.7)	215 (42.6)	543 (41.7)
Type of people visible					
Everyday person	2 (50.0) ^a	65 (56.5) ^b	120 (57.4) ^c	96 (44.6) ^d	283 (52.1) ^e
Model	1 (25.0) ^a	39 (33.9) ^b	59 (28.2) ^c	78 (36.3) ^d	177 (32.6) ^e
Celebrity	1 (25.0) ^a	4 (3.5) ^b	9 (4.3) ^c	15 (7.0) ^d	29 (5.3) ^e
Health professional/academic	0 (0) ^a	0 (0) ^b	3 (1.4) ^c	12 (5.6) ^d	15 (2.8) ^e
Other	0 (0) ^a	7 (6.1) ^b	11 (5.3) ^c	4 (1.9) ^d	22 (4.1) ^e
Multiple types	0 (0) ^a	0 (0) ^b	7 (3.3) ^c	10 (4.6) ^d	17 (3.1) ^e
Gender of people visible					
Female	1 (25.0) ^a	39 (33.9) ^b	44 (21.0) ^c	39 (18.1) ^d	123 (22.7) ^e
Male	3 (75.0) ^a	58 (50.4) ^b	134 (64.1) ^c	131 (60.9) ^d	326 (60.0) ^e
Both	0 (0) ^a	7 (6.1) ^b	15 (7.2) ^c	23 (10.7) ^d	45 (8.3) ^e
Cannot determine	0 (0) ^a	11 (9.6) ^b	16 (7.7) ^c	22 (10.2) ^d	49 (9.0) ^e
Age of people visible (years)					
<18	0 (0) ^f	0 (0) ^g	3 (2.6) ^h	4 (3.2) ⁱ	7 (2.2) ^j
≥18	2 (100.0) ^f	72 (100.0) ^g	111 (95.7) ^h	115 (93.5) ⁱ	300 (95.8) ^j
Mixed	0 (0) ^f	0 (0) ^g	2 (1.7) ^h	4 (3.2) ⁱ	6 (1.9) ^j

^aN=4.^bN=115.^cN=209.^dN=215.^eN=543.^fN=2.^gN=72.^hN=116.ⁱN=123.^jN=313.

Product Placement and Visibility

A vaporizer product was visible in 70% (913/1303) of images, and most commonly (497/1303, 38.14%) these were e-cigarette or other vaping devices (eg, e-hookah, e-cigar; [Table 3](#)).

E-cigarette liquids (also known as e-liquid or e-juice) were present in 11.82% (154/1303) of images. In posts that depicted a vaporizer product, the product was placed overtly within the image in 92.7% (846/913) of posts.

Table 3. Frequency statistics for each year corpus and the total sample within the “vape and tobacco products” domain.

Associated codes	2012 (N=12), n (%)	2014 (N=246), n (%)	2016 (N=540), n (%)	2018 (N=505), n (%)	Total (N=1303), n (%)
Product placement^a					
Overt	8 (88.9) ^b	179 (94.2) ^c	373 (93.5) ^d	286 (90.8) ^e	846 (92.7) ^f
Covert	1 (11.1) ^b	11 (5.8) ^c	26 (6.5) ^d	29 (9.2) ^e	67 (7.3) ^f
Product visible					
E-cigarette or another vaping device	3 (25.0) ^b	116 (47.2) ^c	199 (36.9) ^d	149 (35.4) ^e	497 (38.1) ^f
E-cigarette and another vape/tobacco product	2 (16.7) ^b	37 (15.0) ^c	79 (14.6) ^d	37 (7.3) ^e	155 (11.9) ^f
Vape accessory	0 (0) ^b	11 (4.5) ^c	28 (5.2) ^d	22 (4.4) ^e	61 (4.7) ^f
Vape liquid (e-liquid)	1 (8.3) ^b	17 (6.9) ^c	84 (15.6) ^d	52 (10.3) ^e	154 (11.8) ^f
Vape liquid and another vape/tobacco product	1 (8.0) ^b	0 (0) ^c	0 (0) ^d	5 (1.0) ^e	6 (0.5) ^f
Showcase in a retail store	0 (0) ^b	6 (2.4) ^c	4 (0.7) ^d	5 (1.0) ^e	15 (1.2) ^f
Tobacco product	2 (16.7) ^b	3 (1.2) ^c	4 (0.7) ^d	14 (2.8) ^e	23 (1.8) ^f
Setting					
Indoors	4 (66.7) ^g	94 (77.7) ^h	173 (71.2) ⁱ	107 (60.1) ^j	378 (69.0) ^k
Outdoors	2 (33.3) ^g	27 (22.3) ^h	70 (28.8) ⁱ	71 (39.9) ^j	170 (31.0) ^k

^aOnly coded for if a product was visible in the post.

^bN=9.

^cN=190.

^dN=399.

^eN=315.

^fN=913

^gN=6.

^hN=121.

ⁱN=243.

^jN=178.

^kN=548.

Promotional Practices and Strategies

In 26.63% (347/1303) of posts, purchase of e-cigarette products was promoted, and 9.67% (126/1303) of posts provided Twitter users with a promotional offer (Table 4). Promotional offers could be monetary or nonmonetary, of which nonmonetary offers were most prevalent (86/126, 68.3%). Nonmonetary promotional offers did not lower the cost of a purchase; they instead promoted contests, giveaways, and sweepstakes or offered free shipping or a free gift with purchase. Rather than aiming to sell specific e-cigarette products, some posts promoted vape businesses, brands, and online groups. These posts were categorized as “business listings” and comprised 19.95% (260/1303) of the total sample (Figure 1). Some business listings and promotional posts used methods to increase their visibility

and expand their market, such as operating competitions to win e-cigarette products. However, to enter a competition, Twitter users were required to undertake a series of steps including following the account, and liking, commenting, re-tweeting, or tagging others in the post (Figure 2).

Of posts that displayed or discussed e-liquid products, 71.1% (226/318) described the flavor of the product through either words or images (eg, images of candy or fruits; Figure 3). Creative flavor names (eg, King Cookie Dough, Show me the Honey) and descriptive flavor descriptions (eg, “Grab a sweet and spicy cup of tea from the Chai Wallah as he makes the rounds on an overcrowded train slowly making its way to Varanasi”) were commonly depicted in image captions and on product packaging.

Table 4. Frequency statistics for each year corpus and the total sample within the “promotional practices and strategies” domain.

Associated codes	2012 (N=12), n (%)	2014 (N=246), n (%)	2016 (N=540), n (%)	2018 (N=505), n (%)	Total (N=1303), n (%)
E-liquid flavor described (yes) ^a	3 (100.0) ^b	33 (58.9) ^c	144 (90.0) ^d	76 (76.8) ^e	226 (71.1) ^f
Product brand or logo visible (yes) ^g	4 (44.4) ^h	83 (43.7) ⁱ	230 (57.6) ^j	144 (45.7) ^k	461 (50.5) ^l
Product brand or logo is visible anywhere	4 (33.3)	128 (52.0)	275 (50.9)	211 (41.8)	618 (47.4)
Promoting vape product for purchase	2 (16.7)	80 (32.5)	164 (30.4)	101 (20.0)	347 (26.6)
Business listing	2 (16.7)	61 (24.8)	101 (18.7)	96 (19.0)	260 (20.0)
Vapor present	1 (8.3)	60 (24.4)	104 (19.3)	89 (17.6)	254 (19.5)
Promotional offer					
Monetary	0 (0) ^m	11 (42.3) ⁿ	15 (31.9) ^o	7 (7.8) ^p	33 (26.2) ^q
Nonmonetary	1 (100.0) ^m	14 (53.8) ⁿ	29 (61.7) ^o	45 (86.5) ^p	89 (70.6) ^q
Both	0 (0) ^m	1 (3.8) ⁿ	3 (6.4) ^o	0 (0.0) ^p	4 (3.2) ^q
Vape product review	0 (0)	7 (2.8)	36 (6.7)	29 (5.7)	72 (5.5)
Cartoon	1 (8.3)	8 (3.3)	31 (5.7)	18 (3.6)	58 (4.5)
Sale notice	0 (0)	3 (1.2)	11 (2.0)	1 (0.2)	15 (1.2)

^aOnly coded for if the post displayed or discussed an e-liquid product.

^bN=3.

^cN=56.

^dN=160.

^eN=99.

^fN=318.

^gOnly coded for if a vaping-related product was visible in the post.

^hN=9.

ⁱN=190.

^jN=399.

^kN=315.

^lN=913.

^mN=1.

ⁿN=26.

^oN=47.

^pN=52.

^qN=126.

Figure 1. Example within the business listing category of the "promotional practices and strategies" domain.



Figure 2. Example within the nonmonetary promotional offer category of the "promotional practices and strategies" domain.



Figure 3. Example of a flavor within the "promotional practices and strategies" domain.



Health, Safety, and Product Claims

The potential health benefits and consequences (Figure 4) of e-cigarettes were detailed in 9.90% (129/1303) of posts, of which 70.5% (91/129) conveyed the perceived benefits associated with e-cigarette use (Table 5). These posts compared e-cigarette products to their presumed more harmful counterpart, combustible cigarettes, by listing the alleged harmless ingredients found in vaporizer products (eg, nicotine, propylene

glycol, glycerin, flavoring; Figure 5) compared to the toxic ingredients found in tobacco cigarettes (eg, ammonia, carbon monoxide, lead), labelled e-cigarettes as “smoke-free,” publicized that e-cigarettes provide a “safe” or “safer” smoking experience, and included testimonials from people who had quit smoking through the use of e-cigarettes and their subsequent positive changes in health. Further, a significant proportion of posts promoted e-cigarettes as an effective smoking cessation aid (266/1303, 20.41%; Figure 6).

Figure 4. Example of health consequences being explained within the “health, safety, and product claims” domain.



Table 5. Frequency statistics for each year corpus and the total sample within the “health, safety, and product claims” domain.

Associated codes	2012 (N=12), n (%)	2014 (N=246), n (%)	2016 (N=540), n (%)	2018 (N=505), n (%)	Total (N=1303), n (%)
Quit smoking	7 (58.3)	52 (21.1)	96 (17.8)	111 (22.0)	266 (20.4)
Health					
Total	1 (8.3)	15 (6.1)	34 (6.3)	79 (15.6)	129 (9.9)
Positive	1 (100.0)	13 (86.7)	22 (64.7)	55 (69.6)	91 (75.2)
Negative	0 (0)	2 (13.3)	12 (35.3)	24 (30.4)	38 (29.5)
Safety	0 (0)	8 (3.3)	30 (5.6)	24 (4.8)	62 (4.8)
Public health	0 (0)	2 (0.8)	18 (3.3)	30 (5.9)	50 (3.8)
Youth vaping	0 (0)	3 (1.2)	8 (1.5)	31 (6.1)	42 (3.2)
Health warning or age restriction visible	0 (0)	3 (1.2)	8 (1.5)	14 (2.8)	25 (1.9)
Nicotine^a					
Nicotine level (mg)	0 (0) ^b	4 (8.7) ^c	27 (18.1) ^d	3 (3.9) ^e	34 (12.4) ^f
Nicotine-free	1 (50.0) ^b	1 (2.3) ^c	9 (6.0) ^d	9 (11.7) ^e	20 (7.3) ^f
Multiple products: nicotine and nicotine-free	0 (0) ^b	2 (4.3) ^c	2 (1.3) ^d	1 (1.3) ^e	5 (1.8) ^f
No nicotine level visible	1 (50.0) ^b	39 (84.8) ^c	111 (74.5) ^d	64 (83.1) ^e	215 (78.5) ^f

^aOnly coded for if the post displayed an e-liquid product.

^bN=2.

^cN=46.

^dN=149.

^eN=77.

^fN=274.

Figure 5. Example of an explanation of e-liquid ingredients within the “health, safety, and product claims” domain.

WHAT'S IN E-CIGARETTE LIQUID?

Propylene Glycol
Food additive (E1520)
Has been a food additive for over 50 years. Non-toxic and considered generally safe for consumption by the US FDA. Used in ice-cream, confectionery, hand creams, cosmetics and pharmaceuticals.

Vegetable glycerol
Food additive (E422) derived from plants, usually soybeans or palm. Used in food and beverages, toothpaste, mouth-wash, gel tablets, glycerol soap and widely in pharmaceutical formulations.



Food flavouring
E-liquid alone has little taste, so flavour concentrates such as vanilla, mint, fruit, beverage, confectionery, tobacco and spices are usually added.

Nicotine
Stimulant found in tomatoes, eggplant, cauliflower and especially tobacco leaf. Typical e-liquid contains a 1 to 3% concentration of nicotine. A drop of typical e-liquid contains 0.5 to 1mg of nicotine (compared to nicotine gum with 2 to 4mg).

Figure 6. Example of describing e-cigarettes as a smoking cessation aid within the “health, safety, and product claims” domain.

What's an effective alternative for smokers who can't quit?

There is clear evidence that vaping has helped millions of smokers to quit



Australian Tobacco Harm Reduction Association

Only 1.92% (25/1303) of posts contained a health warning or age restriction. Health warnings were commonly displayed on e-cigarette product packaging (Figure 7). Age restrictions indicating products were not to be used by those under the age of 18 years were commonly asserted by a small icon, similar to

that found on alcoholic beverages in Australia. Of the posts that portrayed an e-liquid product, 21.5% (59/274) identified whether the product contained nicotine (eg, 2 mg) or was nicotine-free (eg, 0 mg).

Figure 7. Example of a health warning within the “health, safety, and product claims” domain.



Behaviors and Practices

Over half (709/1303, 54.41%) of all posts indicated the presence of a vaping community or shared social identity or addiction bond, commonly through the use of hashtags. Popular hashtags that accompanied these posts included #vapecommunity, #vapefam, #vapenation, and #vapelife. One user posted:

#vape #vapefam #WeVapeWeVote #vapenation As a show of solidarity, I will add your #THR [tobacco

harm reduction] medal to your profile pic[ture] if you'd like. Simply send me a DM [direct message] w/ [with] the picture and it can be done quickly.

“Hand check/product check” posts (255/1303, 19.57%) often appeared as simple photographs of an e-cigarette device or liquid in the hand of its user (Figure 8) or standalone (Table 6). These images were commonly taken in people’s homes, cars, and other outdoor locations and were frequently accompanied by the hashtag #handcheck.

Figure 8. Example of a hand check post within the “behaviors and practices” domain.



Table 6. Frequency statistics for each year corpus and the total sample within the “behaviors and practices” and “association with another substance” domains.

Associated codes	2012 (N=12), n (%)	2014 (N=246), n (%)	2016 (N=540), n (%)	2018 (N=505), n (%)	Total (N=1303), n (%)
Behaviors and practices domain					
Identity or community	0 (0)	142 (57.7)	341 (63.1)	226 (44.8)	709 (54.4)
Hand check/product check	4 (33.3)	45 (18.3)	127 (23.5)	79 (15.6)	255 (19.6)
Selfie	0 (0)	17 (6.9)	24 (4.4)	14 (2.8)	55 (4.2)
Building/DIY ^a	1 (8.3)	10 (4.1)	21 (3.9)	18 (3.6)	50 (3.8)
Meme	0 (0)	4 (1.6)	17 (3.1)	26 (5.1)	47 (3.6)
Vape play	0 (0)	12 (4.9)	21 (3.9)	10 (2.0)	43 (3.3)
Person vaping	1 (8.3)	71 (28.9)	99 (18.3)	90 (17.8)	261 (20.0)
Erotic or sexualized	0 (0)	7 (2.8)	11 (2.0)	1 (0.2)	19 (1.5)
Association with another substance domain					
Cannabis (including hemp)	0 (0) ^b	1 (25.0) ^c	11 (61.1) ^d	11 (91.7) ^e	23 (67.6) ^f
Alcohol	0 (0) ^b	3 (75.0) ^c	7 (38.9) ^d	1 (8.3) ^e	11 (32.4) ^f

^aDIY: do-it-yourself.

^bN=0.

^cN=4.

^dN=18.

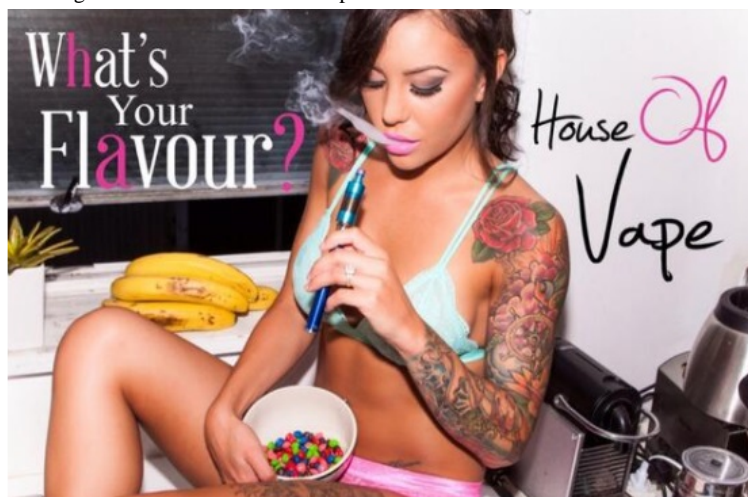
^eN=12.

^fN=34.

Men were more often represented in selfies (40/55, 73%; $P<.001$), and in posts of people vaping (139/261, 53.3%; $P<.001$) and performing vape tricks (25/43, 58%; $P<.001$; [Figure 9](#)) than women (selfies: 12/55, 22%; vaping: 84/261, 32.2%; performing vape tricks: 8/43, 19%). Furthermore, men more frequently posted “hand check/product checks” (98/255, 38.4%; $P<.001$) and posts that indicated a connection with the vape

community or vaper identity (199/709, 28.1%; $P=.05$) than women (12/255, 4.7% and 60/709, 8.5%, respectively). A person was present in 18 of the 19 “erotic or sexualized” posts, of which 16 (89%) images contained women scantily dressed and suggestively posed ([Figure 10](#)). The remaining 2 images portrayed a man and woman together.

Figure 9. Example of male representation within the “behaviors and practices” domain.

Figure 10. Example of a sexualized image within the "behaviors and practices" domain.

Regulation and Advocacy

E-cigarette regulation and policy were discussed in 10.74% (140/1303) of posts (Table 7). An almost equal proportion of posts was found to be discussing or in favor of liberal (90/1303,

6.91%) versus restrictive (87/1303, 6.68%; Figure 11) e-cigarette policies. Advocacy efforts were encouraged in 4.99% (65/1303) of posts, of which 60% (39/65) supported liberal e-cigarette regulation (Figure 12).

Table 7. Frequency statistics for each year corpus and the total sample within the "regulation and advocacy" domain.

Associated codes	2012 (n=12), n (%)	2014 (n=246), n (%)	2016 (n=540), n (%)	2018 (n=505), n (%)	Total (n=1303), n (%)
Regulation or policy	0 (0)	9 (3.7)	43 (8.0)	100 (19.8)	140 (10.7)
Liberal regulation	0 (0)	6 (2.4)	26 (4.8)	58 (11.5)	90 (6.9)
Restrictive regulation	0 (0)	2 (0.8)	27 (5.0)	58 (11.5)	87 (6.7)
Advocacy	0 (0)	3 (1.2)	16 (3.0)	46 (9.1)	65 (5.0)

Figure 11. Example of a restrictive policy within the "regulation and advocacy" domain.

Figure 12. Example of advocacy within the "regulation and advocacy" domain.



Discussion

Promotional Practices and Strategies

The use of several promotional practices and strategies was documented in this study, namely the promotion of positive perceptions of e-cigarette use, implicit and explicit marketing of e-cigarette products and businesses, and the use of promotional offers (monetary and nonmonetary). These findings are consistent with those reported in a recent systematic review of e-cigarette marketing communication [44] and are known and effective strategies utilized by the tobacco industry for decades [45]. These promotional practices coupled with the ease in which consumers can purchase products online through the click of a link have resulted in the exponential growth of online e-cigarette sales worldwide [46]. Investigations into youth online purchasing have confirmed the ease with which young people can purchase e-cigarette products due to the lack of appropriate age detection processes [47-49].

The promotion of e-liquid flavors through images, detailed flavor descriptions, and appealing product packaging was common and is supported by other social media-based investigations [50,51]. E-cigarette users commonly report the importance of flavored e-cigarette products in facilitating smoking abstinence and enhancement of their vaping experience [52]. Subsequently, e-cigarette manufacturers and retailers have adopted the promotion of flavored e-cigarette products as a major marketing strategy [53]. However, evidence indicates the promotion of flavored e-liquid may be particularly attractive to young people [54] and serve as one of the main reasons for e-cigarette initiation [55]. Furthermore, youth have been found to perceive fruit-flavored e-liquids to be less harmful than tobacco-flavored products [56], and fruit-flavored e-liquids have been linked to greater perceived enjoyment [57].

Health, Safety and Product Claims

It is not uncommon to find posts on social media claiming e-cigarettes are safer than cigarettes and can be used as a cessation tool, with limited or no validation [35]. Only a very

small proportion of posts in this study was accompanied by or depicted a health warning or age restriction, and an increasing proportion of posts was found to be promoting the positive health effects of vaping. Furthermore, a substantial proportion of posts promoted e-cigarettes as a replacement or alternative to cigarettes, similar to that found by Laestadius and colleagues [30]. Risk perception plays an important role in product use decision making, and a commonly cited reason for e-cigarette uptake among adults and young people is the belief that they are less harmful than cigarettes [58-60]. Youth who perceive e-cigarettes as harmless or less harmful than cigarettes are at increased susceptibility of uptake compared to youth with more negative views towards vaping [61,62].

Behaviors and Practices

A common post found in this study, the "hand check/product check," is significant because these posts reflect the variety and wide range of vaporizer and e-liquid products and accessories that exist. As vaporizers continue to evolve, with users able to customize and create unique devices, users are increasingly turning to social media to share the products they are using and creating. Similarly, Chu and colleagues [29] found a large proportion of product-based images posted to the social media platform Instagram exhibiting the hashtag #handcheck. The authors expressed concern regarding this increasing trend, as these images act as unpaid marketing of e-cigarette products and viewers may interpret these devices to be commonplace and socially acceptable.

The inclusion of hashtags such as #vapecommunity, #vapelifelife, #vapenation, and #cloudchaser demonstrate the existence of a vaping identity and community on Twitter, which has also been found in prior vaping-related social media investigations [30,63]. Inclusion of such hashtags may function to create an internalization of social bonding and a vape-related identity [63]. This internalization may help one to define who they are and create their own identity and values within a society that has normalized values and practices. This has led to the formation of unique online and face-to-face "vaper"

communities and identities [64,65], which some people are now adopting and associating with rather than the identity of being a “cigarette smoker” or “ex-smoker.” The application of hashtags to social media posts is a form of folksonomy, and the initiating adopters of these electronic tags and subsequent uptake by imitators can be explained by Roger’s Diffusion of Innovation Theory, which seeks to explain how, why, and at what rate new ideas and technology spread [66]. It has therefore been suggested by some that these vaping-related discussions may be occurring within some networks as an “echo chamber,” whereby the ideas and beliefs of those within the network are strengthened, resulting in the normalization of vaping within these communities [63]. Research examining Australian Twitter users using network analysis methods could provide an Australian perspective on this hypothesis. Further, research that examines how nicotine addiction is represented on social media may assist to understand evolving perceptions of addiction and identity.

Implications for Policy and Research

This investigation demonstrates that a number of Australian Twitter users are purposefully (commercial) and also inadvertently (through posts by vapers) promoting the use of e-cigarettes. Twitter has a “paid” advertising policy prohibiting the promotion of tobacco products, accessories, and branding (including e-cigarettes) [67]. The policy, however, does not relate to individual account holder’s content, fan pages, or groups. The boundaries between owned, paid, earned, and shared content have become increasingly more blurred [68], with evidence suggesting influencers are being used to circumvent social media policies [69,70]. In the absence of regulations controlling online promotions and formal gateways restricting access to content, posts on social media platforms such as Twitter can reach and potentially influence both e-cigarette users and nonusers alike [51]. Exploring opportunities to further restrict the commercial promotion of these devices (ie, unpaid promotion from commercial accounts) on Twitter and other social media platforms is required, and working with social media platforms to voluntarily employ these restrictions is one possible solution [71].

This study found the proportion of posts specifically promoting e-cigarette products for purchase decreased in 2018 ([Multimedia Appendix 1](#)), although this correlates with a relative decline in Twitter use by Australians in comparison to other larger and growing platforms. Due to the increased popularity of Instagram over recent years, and more recently TikTok, it would be valuable to investigate e-cigarette–related promotional content posted to these platforms. Instagram and TikTok are primarily photo and video-sharing social networking services; therefore, these platforms may be more desirable and more highly accessed than Twitter to share this type of content.

A product for therapeutic use, such as smoking cessation or alleviation of nicotine withdrawal, must be registered with the

Therapeutic Goods Administration to be sold lawfully in Australia [2]. At present, no heated tobacco nor nicotine vaporizer has been approved by the Therapeutic Goods Administration and therefore should not be promoted as a smoking cessation product. Continued monitoring of Australian e-cigarette retailers to ensure misleading health and smoking cessation claims are not being made is therefore important so as not to contribute further to the confusion regarding e-cigarette safety and efficacy.

Limitations

Several limitations need to be considered when interpreting the results of this study. This study reflects data from one social media platform, Twitter, as its data are mostly public and easily accessible to researchers, whereas some other social media platforms are not as readily accessible [72]. However, the TrISMA infrastructure makes Australian-specific historical Twitter data accessible in a way most other social media platforms do not. This is not an indication that other social media platforms are not spaces where e-cigarettes are discussed by Australians, but only that these activities are not always as visible to researchers. The search strategy included several popular terms used to describe e-cigarettes and vaping practices; however, emerging and variations of slang terms may have been overlooked. The investigation focused only on tweets that included an image. Therefore, these results may not be reflective of all tweets by Australian users. Lastly, we relied on TrISMA’s programmed bot filtering processes occurring at the level of the user before tweets were collected to remove questionable accounts. Future studies examining Twitter data are encouraged to apply denoising techniques after data collection [73].

Conclusions

Despite Australia’s cautious approach toward e-cigarettes and the limited evidence supporting e-cigarettes as an efficacious smoking cessation aid, it is evident that there is a concerted effort by some Twitter users to promote these devices as a harmless, health-conducive, smoking cessation product. Further, Twitter is being used in an attempt to circumvent Australian regulation and advocate for a liberal approach to personal vaporizers. The borderless nature of social media presents a clear challenge for enforcing Article 13 of the WHO FCTC. Evidence suggests a relationship exists between e-cigarette advertising exposure and uptake, and social media is now being used to generate favorable attitudes towards vaporizer products. As “digital media” consumption has increased, content that was previously inaccessible due to conventional advertising regulations, such as tobacco advertising, is now visible, and traditional tobacco control regulations are no longer adequate. The internet is the perfect platform to promote e-cigarettes and novel nicotine products, even in a highly regulated country such as Australia. Countering the advertising and promotion of these products is a public health challenge that will require cross-border cooperation with other WHO FCTC parties.

Acknowledgments

This work was supported by a Healthway Exploratory Research Grant (grant number 32803) and an Australian Government Research Training Program Scholarship. The scholarship is provided by the Commonwealth of Australia to support the general living costs for students (KM) undertaking Research Doctorate studies. This research was also supported by the Faculty of Health Sciences, Curtin University 2019 Health Sciences Summer Scholarship Initiative. The scholarship is provided to support the general living costs of undergraduate students (KT) to undertake a research project. All funders had no role in the design of the study; in the collection, analyses, or interpretation of data; in the writing of the manuscript; and in the decision to publish the results. This research was also supported by infrastructure provided through the Australian Research Council-funded project *TrISMA: Tracking Infrastructure for Social Media Analysis* (LIEF grant LE140100148).

We would like to acknowledge Dr Kevin Chai, Dr Alkim Ozaygen, and Dr Yun Zhao from Curtin University for their assistance with data collection and statistical analyses. We would also like to thank the Cancer Council Western Australia, Australian Council on Smoking and Health, Public Health Advocacy Institute of Western Australia, and Royal Australian College of General Practitioners Western Australia for being members of the study's advisory committee; they provided advice to the research team to help guide the implementation of the project, use of generated data, and dissemination of the research findings.

Authors' Contributions

JJ, BM, TL, KW, and KM acquired the funding. KM, JJ, BM, TL, and KW conceptualized the study and methodology. KM performed project administration, curated the data, and wrote the original draft of the manuscript. JJ, BM, and TL supervised the study. KM and KT performed the formal analysis. Review and editing of the manuscript was performed by BF, JJ, BM, KW, and TL.

Conflicts of Interest

BF is a member of the NHMRC Electronic Cigarettes Working Committee (May 2020). She has received consulting payment for e-cigarette policy review for the New South Wales National Heart Foundation (December 2019). She had travel expenses (flight and registration) reimbursed to attend Oceania Tobacco Control Conference 2017 to present on e-cigarette and cessation. She provided her opinion (unpaid) at the Australian Parliament's Standing Committee on Health, Aged Care and Sport public hearing into the Use and Marketing of Electronic Cigarettes and Personal Vaporisers (September 8, 2017). She led a contract on e-cigarette regulation in Australia for the Commonwealth Department of Health (2016). She had travel expenses reimbursed by National Taiwan University for presenting on e-cigarette regulation (2016). The other authors have no conflicts to declare.

Multimedia Appendix 1

Coding framework.

[[DOCX File, 20 KB - publichealth_v6i4e15577_app1.docx](#)]

References

1. Legal status of electronic cigarettes in Australia. Quit Victoria. 2016. URL: <https://www.quit.org.au/documents/77/legal-status-electronic-cigarettes-australia.pdf> [accessed 2019-05-27]
2. Therapeutic Goods Administration. Electronic cigarettes. Australian Government Department of Health. 2019. URL: <https://www.tga.gov.au/community-qa/electronic-cigarettes> [accessed 2019-06-24]
3. NicoPharm. 2019. URL: <http://nicopharm.com.au/> [accessed 2019-11-06]
4. Greenhalgh EM, Grace C, Scollo MM. 18B.8: Legal status in Australia. Tobacco in Australia: Facts and issues. Melbourne, Victoria, Australia: Cancer Council Victoria; 2019. URL: <https://www.tobaccoinaustralia.org.au/chapter-18-harm-reduction/indepth-18b-e-cigarettes/18b-9-legal-status> [accessed 2019-11-06]
5. Australian Border Force. Tobacco. Prohibited goods. 2020. URL: <https://www.abf.gov.au/importing-exporting-and-manufacturing/prohibited-goods/categories/tobacco> [accessed 2020-10-16]
6. World Health Organization. Guidelines for implementation of Article 13: Guidelines on tobacco advertising, promotion and sponsorship. WHO Framework Convention on Tobacco Control. 2008. URL: https://www.who.int/fctc/guidelines/adopted/article_13/en/ [accessed 2020-10-16]
7. NSW Government. Electronic cigarettes. 2019. URL: <https://www.health.nsw.gov.au/tobacco/Pages/e-cigarettes.aspx> [accessed 2020-03-04]
8. Government of South Australia. Selling e-cigarettes in South Australia - retailer fact sheet. Drug and Alcohol Services South Australia. 2019. URL: <https://www.sahealth.sa.gov.au/wps/wcm/connect/f3a6e0fa-762a-4be0-acfa-09a9a11e1b4c/Selling+E-Cigarettes+in+SA+-+Retailer+Fact+Sheet+200319.pdf> [accessed 2020-03-04]
9. Tasmanian Government. Tobacco control - Electronic cigarettes. 2019. URL: https://www.dhhs.tas.gov.au/publichealth/tobacco_control/electronic-cigarettes [accessed 2020-03-04]
10. Queensland Government. Electronic cigarettes. Tobacco laws in Queensland. 2019. URL: <https://www.health.qld.gov.au/public-health/topics/atod/tobacco-laws/electronic-cigarettes> [accessed 2020-03-04]

11. Australian Institute of Health and Welfare. National Drug Strategy Household Survey. Canberra: AIHW; 2020. URL: <https://www.aihw.gov.au/about-our-data/our-data-collections/national-drug-strategy-household-survey#:~:text=The%20National%20Drug%20Strategy%20Household,alcohol%20and%20other%20drug%20use> [accessed 2020-10-16]
12. McCausland K, Maycock B, Jancey J. The messages presented in online electronic cigarette promotions and discussions: a scoping review protocol. *BMJ Open* 2017;7(11):e018633. [doi: [10.1136/bmjopen-2017-018633](https://doi.org/10.1136/bmjopen-2017-018633)] [Medline: [29122804](https://pubmed.ncbi.nlm.nih.gov/29122804/)]
13. Chen AT, Zhu S, Conway M. What Online Communities Can Tell Us About Electronic Cigarettes and Hookah Use: A Study Using Text Mining and Visualization Techniques. *J Med Internet Res* 2015;17(9):e220 [FREE Full text] [doi: [10.2196/jmir.4517](https://doi.org/10.2196/jmir.4517)] [Medline: [26420469](https://pubmed.ncbi.nlm.nih.gov/26420469/)]
14. Ayers JW, Leas EC, Allem J, Benton A, Dredze M, Althouse BM, et al. Why do people use electronic nicotine delivery systems (electronic cigarettes)? A content analysis of Twitter, 2012-2015. *PLoS One* 2017;12(3):e0170702 [FREE Full text] [doi: [10.1371/journal.pone.0170702](https://doi.org/10.1371/journal.pone.0170702)] [Medline: [28248987](https://pubmed.ncbi.nlm.nih.gov/28248987/)]
15. Allem J, Escobedo P, Chu K, Boley Cruz T, Unger JB. Images of Little Cigars and Cigarillos on Instagram Identified by the Hashtag #swisher: Thematic Analysis. *J Med Internet Res* 2017;19(7):e255 [FREE Full text] [doi: [10.2196/jmir.7634](https://doi.org/10.2196/jmir.7634)] [Medline: [28710057](https://pubmed.ncbi.nlm.nih.gov/28710057/)]
16. Hootsuite, We Are Social. Digital 2019 Australia. Datareportal. 2019. URL: <https://datareportal.com/reports/digital-2019-australia?rq=australia> [accessed 2019-11-06]
17. Bruns A, Stieglitz S. Quantitative Approaches to Comparing Communication Patterns on Twitter. *Journal of Technology in Human Services* 2012;30(3-4):160-185. [doi: [10.1080/15228835.2012.744249](https://doi.org/10.1080/15228835.2012.744249)]
18. Hébert ET, Case KR, Kelder SH, Delk J, Perry CL, Harrell MB. Exposure and Engagement With Tobacco- and E-Cigarette-Related Social Media. *J Adolesc Health* 2017;61(3):371-377 [FREE Full text] [doi: [10.1016/j.jadohealth.2017.04.003](https://doi.org/10.1016/j.jadohealth.2017.04.003)] [Medline: [28669801](https://pubmed.ncbi.nlm.nih.gov/28669801/)]
19. McCausland K, Maycock B, Leaver T, Jancey J. The Messages Presented in Electronic Cigarette-Related Social Media Promotions and Discussion: Scoping Review. *J Med Internet Res* 2019;21(2):e11953 [FREE Full text] [doi: [10.2196/11953](https://doi.org/10.2196/11953)] [Medline: [30720440](https://pubmed.ncbi.nlm.nih.gov/30720440/)]
20. Kwon M, Park E. Perceptions and Sentiments About Electronic Cigarettes on Social Media Platforms: Systematic Review. *JMIR Public Health Surveill* 2020;6(1):e13673 [FREE Full text] [doi: [10.2196/13673](https://doi.org/10.2196/13673)] [Medline: [31939747](https://pubmed.ncbi.nlm.nih.gov/31939747/)]
21. Vogel EA, Ramo DE, Rubinstein ML, Delucchi KL, Darrow S, Costello C, et al. Effects of Social Media on Adolescents' Willingness and Intention to Use E-Cigarettes: An Experimental Investigation. *Nicotine Tob Res* 2020. [doi: [10.1093/ntr/ntaa003](https://doi.org/10.1093/ntr/ntaa003)] [Medline: [31912147](https://pubmed.ncbi.nlm.nih.gov/31912147/)]
22. Camenga D, Gutierrez KM, Kong G, Cavallo D, Simon P, Krishnan-Sarin S. E-cigarette advertising exposure in e-cigarette naïve adolescents and subsequent e-cigarette use: A longitudinal cohort study. *Addict Behav* 2018;81:78-83 [FREE Full text] [doi: [10.1016/j.addbeh.2018.02.008](https://doi.org/10.1016/j.addbeh.2018.02.008)] [Medline: [29432916](https://pubmed.ncbi.nlm.nih.gov/29432916/)]
23. Pokhrel P, Fagan P, Herzog TA, Laestadius L, Buente W, Kawamoto CT, et al. Social media e-cigarette exposure and e-cigarette expectancies and use among young adults. *Addict Behav* 2018;78:51-58 [FREE Full text] [doi: [10.1016/j.addbeh.2017.10.017](https://doi.org/10.1016/j.addbeh.2017.10.017)] [Medline: [29127784](https://pubmed.ncbi.nlm.nih.gov/29127784/)]
24. Wagoner KG, Reboussin DM, King JL, Orlan E, Cornacchione Ross J, Sutfin EL. Who Is Exposed to E-Cigarette Advertising and Where? Differences between Adolescents, Young Adults and Older Adults. *Int J Environ Res Public Health* 2019;16(14) [FREE Full text] [doi: [10.3390/ijerph16142533](https://doi.org/10.3390/ijerph16142533)] [Medline: [31315189](https://pubmed.ncbi.nlm.nih.gov/31315189/)]
25. Ghosh A, Coakley RC, Mascenik T, Rowell TR, Davis ES, Rogers K, et al. Chronic E-Cigarette Exposure Alters the Human Bronchial Epithelial Proteome. *Am J Respir Crit Care Med* 2018;198(1):67-76 [FREE Full text] [doi: [10.1164/rccm.201710-2033OC](https://doi.org/10.1164/rccm.201710-2033OC)] [Medline: [29481290](https://pubmed.ncbi.nlm.nih.gov/29481290/)]
26. The Lancet. E-cigarettes: time to realign our approach? *Lancet* 2019;394(10206):1297. [doi: [10.1016/S0140-6736\(19\)32277-9](https://doi.org/10.1016/S0140-6736(19)32277-9)] [Medline: [31609211](https://pubmed.ncbi.nlm.nih.gov/31609211/)]
27. Muthumalage T, Prinz M, Anshah KO, Gerloff J, Sundar IK, Rahman I. Inflammatory and Oxidative Responses Induced by Exposure to Commonly Used e-Cigarette Flavoring Chemicals and Flavored e-Liquids without Nicotine. *Front Physiol* 2017;8:1130 [FREE Full text] [doi: [10.3389/fphys.2017.01130](https://doi.org/10.3389/fphys.2017.01130)] [Medline: [29375399](https://pubmed.ncbi.nlm.nih.gov/29375399/)]
28. Bruns A, Burgess J, Banks J, Tjondronegoro D, Dreiling A, Hartley J, et al. TrISMA: Tracking Infrastructure for Social Media Analysis. QUT Digital Media Research Centre. 2016. URL: <http://trisma.org/> [accessed 2019-06-01]
29. Chu K, Allem J, Cruz TB, Unger JB. Vaping on Instagram: cloud chasing, hand checks and product placement. *Tob Control* 2016;26(5):575-578 [FREE Full text] [doi: [10.1136/tobaccocontrol-2016-053052](https://doi.org/10.1136/tobaccocontrol-2016-053052)] [Medline: [27660111](https://pubmed.ncbi.nlm.nih.gov/27660111/)]
30. Laestadius LI, Wahl MM, Cho YI. #Vapelife: An Exploratory Study of Electronic Cigarette Use and Promotion on Instagram. *Subst Use Misuse* 2016;51(12):1669-1673. [doi: [10.1080/10826084.2016.1188958](https://doi.org/10.1080/10826084.2016.1188958)] [Medline: [27484191](https://pubmed.ncbi.nlm.nih.gov/27484191/)]
31. Laestadius LI, Wahl MM, Pokhrel P, Cho YI. From Apple to Werewolf: A content analysis of marketing for e-liquids on Instagram. *Addict Behav* 2019;91:119-127 [FREE Full text] [doi: [10.1016/j.addbeh.2018.09.008](https://doi.org/10.1016/j.addbeh.2018.09.008)] [Medline: [30253933](https://pubmed.ncbi.nlm.nih.gov/30253933/)]
32. Lee A, Hart J, Sears C, Walker K, Siu A, Smith C. A picture is worth a thousand words: Electronic cigarette content on Instagram and Pinterest. *Tob Prev Cessat* 2017;3 [FREE Full text] [doi: [10.18332/tpc/74709](https://doi.org/10.18332/tpc/74709)] [Medline: [28815224](https://pubmed.ncbi.nlm.nih.gov/28815224/)]
33. Cortese DK, Szczycka G, Emery S, Wang S, Hair E, Vallone D. Smoking Selfies: Using Instagram to Explore Young Women's Smoking Behaviors. *Social Media + Society* 2018;4(3):1-8 [FREE Full text] [doi: [10.1177/2056305118790762](https://doi.org/10.1177/2056305118790762)]

34. Ritter SL. Heating up the debate: e-cigarettes and Instagram. Electronic Thesis and Dissertation Repository. 2015. URL: <https://ir.lib.uwo.ca/etd/3350> [accessed 2019-06-01]
35. Cole-Lewis H, Pugatch J, Sanders A, Varghese A, Posada S, Yun C, et al. Social Listening: A Content Analysis of E-Cigarette Discussions on Twitter. *J Med Internet Res* 2015;17(10):e243 [FREE Full text] [doi: [10.2196/jmir.4969](https://doi.org/10.2196/jmir.4969)] [Medline: [26508089](https://pubmed.ncbi.nlm.nih.gov/26508089/)]
36. Unger JB, Escobedo P, Allem J, Soto DW, Chu K, Cruz T. Perceptions of Secondhand E-Cigarette Aerosol Among Twitter Users. *Tob Regul Sci* 2016;2(2):146-152 [FREE Full text] [doi: [10.18001/TRS.2.2.5](https://doi.org/10.18001/TRS.2.2.5)] [Medline: [28090560](https://pubmed.ncbi.nlm.nih.gov/28090560/)]
37. RANDOM.ORG. Random sequence generator. 2020. URL: <https://www.random.org/sequences/> [accessed 2019-09-10]
38. McBride DM, Anne Doshier B. A comparison of conscious and automatic memory processes for picture and word stimuli: a process dissociation analysis. *Conscious Cogn* 2002;11(3):423-460. [doi: [10.1016/s1053-8100\(02\)00007-7](https://doi.org/10.1016/s1053-8100(02)00007-7)] [Medline: [12435377](https://pubmed.ncbi.nlm.nih.gov/12435377/)]
39. Chang Y, Yu H, Lu H. Persuasive messages, popularity cohesion, and message diffusion in social media marketing. *Journal of Business Research* 2015;68(4):777-782. [doi: [10.1016/j.jbusres.2014.11.027](https://doi.org/10.1016/j.jbusres.2014.11.027)]
40. Townsend L, Wallace C. Social media research: A guide to ethics. The University of Aberdeen. 2016. URL: https://www.gla.ac.uk/media/Media_487729_smx.pdf [accessed 2020-10-16]
41. Schreier M. Qualitative content analysis in practice. London, England: Sage Publications, Inc; 2012.
42. Highfield T, Leaver T. A methodology for mapping Instagram hashtags. *First Monday* 2015;20(1) [FREE Full text] [doi: [10.5210/fm.v20i1.5563](https://doi.org/10.5210/fm.v20i1.5563)]
43. Krippendorff K. Content analysis: An introduction to its methodology. Thousand Oaks, CA: Sage Publications, Inc; 2004.
44. Collins L, Glasser AM, Abudayyeh H, Pearson JL, Villanti AC. E-Cigarette Marketing and Communication: How E-Cigarette Companies Market E-Cigarettes and the Public Engages with E-cigarette Information. *Nicotine Tob Res* 2019;21(1):14-24 [FREE Full text] [doi: [10.1093/ntr/ntx284](https://doi.org/10.1093/ntr/ntx284)] [Medline: [29315420](https://pubmed.ncbi.nlm.nih.gov/29315420/)]
45. Paek H, Reid LN, Jeong HJ, Choi H, Krugman D. Five decades of promotion techniques in cigarette advertising: a longitudinal content analysis. *Health Mark Q* 2012;29(1):1-17. [doi: [10.1080/07359683.2011.623087](https://doi.org/10.1080/07359683.2011.623087)] [Medline: [22416922](https://pubmed.ncbi.nlm.nih.gov/22416922/)]
46. E-cigarette market - Growth, trends and forecast (2020-2025). Mordor Intelligence. 2020. URL: <https://www.mordorintelligence.com/industry-reports/global-e-cigarettes-market-industry> [accessed 2020-09-15]
47. Mackey TK, Miner A, Cuomo RE. Exploring the e-cigarette e-commerce marketplace: Identifying Internet e-cigarette marketing characteristics and regulatory gaps. *Drug Alcohol Depend* 2015;156:97-103. [doi: [10.1016/j.drugalcdep.2015.08.032](https://doi.org/10.1016/j.drugalcdep.2015.08.032)] [Medline: [26431794](https://pubmed.ncbi.nlm.nih.gov/26431794/)]
48. Gurram N, Thomson G, Wilson N, Hoek J. Electronic cigarette online marketing by New Zealand vendors. *N Z Med J* 2019;132(1506):20-33. [Medline: [31778369](https://pubmed.ncbi.nlm.nih.gov/31778369/)]
49. Knopf A. FDA warns against underage use of JUUL, cracks down on sales. *The Brown University Child and Adolescent Behavior Letter* 2018;34(6):3-3. [doi: [10.1002/cbl.30300](https://doi.org/10.1002/cbl.30300)]
50. Soule EK, Sakuma KK, Palafox S, Pokhrel P, Herzog TA, Thompson N, et al. Content analysis of internet marketing strategies used to promote flavored electronic cigarettes. *Addict Behav* 2019;91:128-135. [doi: [10.1016/j.addbeh.2018.11.012](https://doi.org/10.1016/j.addbeh.2018.11.012)] [Medline: [30606627](https://pubmed.ncbi.nlm.nih.gov/30606627/)]
51. Allem J, Majmudar A, Dharmapuri L, Cruz TB, Unger JB. E-liquid-related posts to Twitter in 2018: Thematic analysis. *Addict Behav Rep* 2019;10:100196 [FREE Full text] [doi: [10.1016/j.abrep.2019.100196](https://doi.org/10.1016/j.abrep.2019.100196)] [Medline: [31431917](https://pubmed.ncbi.nlm.nih.gov/31431917/)]
52. Farsalinos K, Romagna G, Tsiapras D, Kyrzopoulos S, Spyrou A, Voudris V. Impact of flavour variability on electronic cigarette use experience: an internet survey. *Int J Environ Res Public Health* 2013;10(12):7272-7282 [FREE Full text] [doi: [10.3390/ijerph10127272](https://doi.org/10.3390/ijerph10127272)] [Medline: [24351746](https://pubmed.ncbi.nlm.nih.gov/24351746/)]
53. Chu K, Unger JB, Cruz TB, Soto DW. Electronic Cigarettes on Twitter - Spreading the Appeal of Flavors. *Tob Regul Sci* 2015;1(1):36-41 [FREE Full text] [doi: [10.18001/TRS.1.1.4](https://doi.org/10.18001/TRS.1.1.4)] [Medline: [27853734](https://pubmed.ncbi.nlm.nih.gov/27853734/)]
54. Hoffman AC, Salgado RV, Dresler C, Faller RW, Bartlett C. Flavour preferences in youth versus adults: a review. *Tob Control* 2016;25(Suppl 2):ii32-ii39 [FREE Full text] [doi: [10.1136/tobaccocontrol-2016-053192](https://doi.org/10.1136/tobaccocontrol-2016-053192)] [Medline: [27633764](https://pubmed.ncbi.nlm.nih.gov/27633764/)]
55. Tsai J, Walton K, Coleman BN, Sharapova SR, Johnson SE, Kennedy SM, et al. Reasons for Electronic Cigarette Use Among Middle and High School Students - National Youth Tobacco Survey, United States, 2016. *MMWR Morb Mortal Wkly Rep* 2018;67(6):196-200 [FREE Full text] [doi: [10.15585/mmwr.mm6706a5](https://doi.org/10.15585/mmwr.mm6706a5)] [Medline: [29447148](https://pubmed.ncbi.nlm.nih.gov/29447148/)]
56. Pepper JK, Ribisl KM, Brewer NT. Adolescents' interest in trying flavoured e-cigarettes. *Tob Control* 2016;25(Suppl 2):ii62-ii66 [FREE Full text] [doi: [10.1136/tobaccocontrol-2016-053174](https://doi.org/10.1136/tobaccocontrol-2016-053174)] [Medline: [27633762](https://pubmed.ncbi.nlm.nih.gov/27633762/)]
57. Soule EK, Rosas SR, Nasim A. Reasons for electronic cigarette use beyond cigarette smoking cessation: A concept mapping approach. *Addict Behav* 2016;56:41-50 [FREE Full text] [doi: [10.1016/j.addbeh.2016.01.008](https://doi.org/10.1016/j.addbeh.2016.01.008)] [Medline: [26803400](https://pubmed.ncbi.nlm.nih.gov/26803400/)]
58. Farsalinos KE, Romagna G, Tsiapras D, Kyrzopoulos S, Voudris V. Characteristics, perceived side effects and benefits of electronic cigarette use: a worldwide survey of more than 19,000 consumers. *Int J Environ Res Public Health* 2014;11(4):4356-4373 [FREE Full text] [doi: [10.3390/ijerph110404356](https://doi.org/10.3390/ijerph110404356)] [Medline: [24758891](https://pubmed.ncbi.nlm.nih.gov/24758891/)]
59. Tomaszewski A. The perceived effects of electronic cigarettes on health by adult users: A state of the science systematic literature review. *J Am Assoc Nurse Pract* 2016;28(9):510-515. [doi: [10.1002/2327-6924.12358](https://doi.org/10.1002/2327-6924.12358)] [Medline: [26997487](https://pubmed.ncbi.nlm.nih.gov/26997487/)]
60. Czoli CD, Fong GT, Mays D, Hammond D. How do consumers perceive differences in risk across nicotine products? A review of relative risk perceptions across smokeless tobacco, e-cigarettes, nicotine replacement therapy and combustible cigarettes. *Tob Control* 2017;26(e1):e49-e58. [doi: [10.1136/tobaccocontrol-2016-053060](https://doi.org/10.1136/tobaccocontrol-2016-053060)] [Medline: [27625408](https://pubmed.ncbi.nlm.nih.gov/27625408/)]

61. Gorukanti A, Delucchi K, Ling P, Fisher-Travis R, Halpern-Felsher B. Adolescents' attitudes towards e-cigarette ingredients, safety, addictive properties, social norms, and regulation. *Prev Med* 2017;94:65-71 [FREE Full text] [doi: [10.1016/j.ypmed.2016.10.019](https://doi.org/10.1016/j.ypmed.2016.10.019)] [Medline: [27773711](https://pubmed.ncbi.nlm.nih.gov/27773711/)]
62. Strong DR, Messer K, White M, Shi Y, Noble M, Portnoy DB, et al. Youth perception of harm and addictiveness of tobacco products: Findings from the Population Assessment of Tobacco and Health Study (Wave 1). *Addict Behav* 2019;92:128-135 [FREE Full text] [doi: [10.1016/j.addbeh.2018.12.005](https://doi.org/10.1016/j.addbeh.2018.12.005)] [Medline: [30623806](https://pubmed.ncbi.nlm.nih.gov/30623806/)]
63. Allem J, Ferrara E, Uppu SP, Cruz TB, Unger JB. E-Cigarette Surveillance With Social Media Data: Social Bots, Emerging Topics, and Trends. *JMIR Public Health Surveill* 2017;3(4):e98 [FREE Full text] [doi: [10.2196/publichealth.8641](https://doi.org/10.2196/publichealth.8641)] [Medline: [29263018](https://pubmed.ncbi.nlm.nih.gov/29263018/)]
64. Farrimond H. A typology of vaping: Identifying differing beliefs, motivations for use, identity and political interest amongst e-cigarette users. *Int J Drug Policy* 2017;48:81-90. [doi: [10.1016/j.drugpo.2017.07.011](https://doi.org/10.1016/j.drugpo.2017.07.011)] [Medline: [28810158](https://pubmed.ncbi.nlm.nih.gov/28810158/)]
65. McCausland K, Jancey J, Leaver T, Wolf K, Freeman B, Maycock B. Motivations for use, identity and the vaper subculture: a qualitative study of the experiences of Western Australian vapers. *BMC Public Health* 2020 Oct 15;20(1):1552 [FREE Full text] [doi: [10.1186/s12889-020-09651-z](https://doi.org/10.1186/s12889-020-09651-z)] [Medline: [33059652](https://pubmed.ncbi.nlm.nih.gov/33059652/)]
66. Chang H. A new perspective on Twitter hashtag use: Diffusion of innovation theory. *Proceedings of the American Society for Information Science and Technology* 2011;47(1):1-4. [doi: [10.1002/meet.14504701295](https://doi.org/10.1002/meet.14504701295)]
67. Twitter. Tobacco and tobacco accessories. Prohibited content policies. 2019. URL: <https://business.twitter.com/en/help/ads-policies/prohibited-content-policies/tobacco-and-tobacco-accessories.html> [accessed 2020-03-04]
68. Macnamara J, Lwin M, Adi A, Zerfass A. 'PESO' media strategy shifts to 'SOEP': Opportunities and ethical dilemmas. *Public Relations Review* 2016;42(3):377-385. [doi: [10.1016/j.pubrev.2016.03.001](https://doi.org/10.1016/j.pubrev.2016.03.001)]
69. Vassey J, Metayer C, Kennedy CJ, Whitehead TP. #Vape: Measuring E-Cigarette Influence on Instagram With Deep Learning and Text Analysis. *Front. Commun* 2020;4(75). [doi: [10.3389/fcomm.2019.00075](https://doi.org/10.3389/fcomm.2019.00075)]
70. Kirkham C. Exclusive: Philip Morris suspends social media campaign after Reuters exposes young 'influencers'. Reuters. 2019. URL: <https://www.reuters.com/article/us-philipmorris-ecigs-instagram-exclusiv/exclusive-philip-morris-suspends-social-media-campaign-after-reuters-exposes-young-influencers-idUSKCN1SH02K> [accessed 2020-03-04]
71. Freeman B. New media and tobacco control. *Tob Control* 2012;21(2):139-144. [doi: [10.1136/tobaccocontrol-2011-050193](https://doi.org/10.1136/tobaccocontrol-2011-050193)] [Medline: [22345236](https://pubmed.ncbi.nlm.nih.gov/22345236/)]
72. Weller K, Bruns A, Burgess J, Mahrt M, Puschmann C. *Twitter and society*. New York, NY: Peter Lang Publishing, Inc; 2014. URL: <http://snurb.info/files/2014/Twitter%20and%20Society%20-%20Metrics%20for%20Understanding%20Communication%20on%20Twitter%20%282014%29.pdf> [accessed 2019-06-24]
73. Allem J, Ferrara E. The Importance of Debiasing Social Media Data to Better Understand E-Cigarette-Related Attitudes and Behaviors. *J Med Internet Res* 2016;18(8):e219 [FREE Full text] [doi: [10.2196/jmir.6185](https://doi.org/10.2196/jmir.6185)] [Medline: [27507563](https://pubmed.ncbi.nlm.nih.gov/27507563/)]

Abbreviations

e-cigarette: electronic cigarette

GIF: graphic interchange format

TrISMA: Tracking Infrastructure for Social Media Analysis

WHO FCTC: World Health Organization Framework Convention on Tobacco Control

Edited by G Eysenbach, R Kukafka; submitted 22.07.19; peer-reviewed by C Weiger, JP Allem; comments to author 21.10.19; revised version received 20.11.19; accepted 12.09.20; published 05.11.20.

Please cite as:

McCausland K, Maycock B, Leaver T, Wolf K, Freeman B, Thomson K, Jancey J

E-Cigarette Promotion on Twitter in Australia: Content Analysis of Tweets

JMIR Public Health Surveill 2020;6(4):e15577

URL: <http://publichealth.jmir.org/2020/4/e15577/>

doi: [10.2196/15577](https://doi.org/10.2196/15577)

PMID: [33151159](https://pubmed.ncbi.nlm.nih.gov/33151159/)

©Kahlia McCausland, Bruce Maycock, Tama Leaver, Katharina Wolf, Becky Freeman, Katie Thomson, Jonine Jancey. Originally published in *JMIR Public Health and Surveillance* (<http://publichealth.jmir.org>), 05.11.2020. This is an open-access article distributed under the terms of the Creative Commons Attribution License (<https://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in *JMIR Public*

Health and Surveillance, is properly cited. The complete bibliographic information, a link to the original publication on <http://publichealth.jmir.org>, as well as this copyright and license information must be included.

Original Paper

Nowcasting Sexually Transmitted Infections in Chicago: Predictive Modeling and Evaluation Study Using Google Trends

Amy Kristen Johnson^{1,2*}, MSW, PhD; Runa Bhaumik^{3*}, PhD; Irina Tabidze^{4*}, MPH, MD; Supriya D Mehta^{3*}, MS, PhD

¹Ann & Robert H. Lurie Children's Hospital of Chicago, Chicago, IL, United States

²Northwestern University, Chicago, IL, United States

³School of Public Health, University of Illinois at Chicago, Chicago, IL, United States

⁴Chicago Department of Public Health, Chicago, IL, United States

* all authors contributed equally

Corresponding Author:

Amy Kristen Johnson, MSW, PhD

Ann & Robert H Lurie Children's Hospital of Chicago

225 E Chicago Avenue

Chicago, IL, 60611

United States

Phone: 1 3122277733

Email: akjohnson@luriechildrens.org

Abstract

Background: Sexually transmitted infections (STIs) pose a significant public health challenge in the United States. Traditional surveillance systems are adversely affected by data quality issues, underreporting of cases, and reporting delays, resulting in missed prevention opportunities to respond to trends in disease prevalence. Search engine data can potentially facilitate an efficient and economical enhancement to surveillance reporting systems established for STIs.

Objective: We aimed to develop and train a predictive model using reported STI case data from Chicago, Illinois, and to investigate the model's predictive capacity, timeliness, and ability to target interventions to subpopulations using Google Trends data.

Methods: Deidentified STI case data for chlamydia, gonorrhea, and primary and secondary syphilis from 2011-2017 were obtained from the Chicago Department of Public Health. The data set included race/ethnicity, age, and birth sex. Google Correlate was used to identify the top 100 correlated search terms with "STD symptoms," and an autocrawler was established using Google Health Application Programming Interface to collect the search volume for each term. Elastic net regression was used to evaluate prediction accuracy, and cross-correlation analysis was used to identify timeliness of prediction. Subgroup elastic net regression analysis was performed for race, sex, and age.

Results: For gonorrhea and chlamydia, actual and predicted STI values correlated moderately in 2011 (chlamydia: $r=0.65$; gonorrhea: $r=0.72$) but correlated highly (chlamydia: $r=0.90$; gonorrhea: $r=0.94$) from 2012 to 2017. However, for primary and secondary syphilis, the high correlation was observed only for 2012 ($r=0.79$), 2013 ($r=0.77$), 2016 (0.80), and 2017 ($r=0.84$), with 2011, 2014, and 2015 showing moderate correlations ($r=0.55-0.70$). Model performance was the most accurate (highest correlation and lowest mean absolute error) for gonorrhea. Subgroup analyses improved model fit across disease and year. Regression models using search terms selected from the cross-correlation analysis improved the prediction accuracy and timeliness across diseases and years.

Conclusions: Integrating nowcasting with Google Trends in surveillance activities can potentially enhance the prediction and timeliness of outbreak detection and response as well as target interventions to subpopulations. Future studies should prospectively examine the utility of Google Trends applied to STI surveillance and response.

(*JMIR Public Health Surveill* 2020;6(4):e20588) doi:[10.2196/20588](https://doi.org/10.2196/20588)

KEYWORDS

health information technology; sexually transmitted infections; surveillance; infoveillance; infodemiology; Google Trends

Introduction

Gonorrhea, chlamydia, and syphilis continue to pose a significant public health challenge with approximately 3.7 million new diagnoses each year in the United States [1]. Rates of sexually transmitted infections (STIs) increased from 2017 to 2018, with gonorrhea, chlamydia, and syphilis showing a rise of 2.9%, 5.0%, and 14.9%, respectively [2]. Despite these documented increases, many cases remain undiagnosed and unreported; as a result, the true burden of these STIs is likely much greater [1]. The purpose of STI surveillance is to estimate the morbidity and mortality of disease as well as enhance the ability to predict and respond to disease patterns. Disparities in the rates of STIs by age, sex, race, and region have been observed; timely and accurate detection of these issues can support effective prevention and control [1].

National surveillance relies on mandatory laboratory and case reporting, a system that produces data that are often incomplete and limited in scope [3]. In addition to data quality concerns, underreporting and reporting delays result in missed opportunities to identify and respond to trends in disease and limit the ability to guide STI control [3,4]. Although web-based and electronic systems for laboratory and provider reporting can increase response timeliness, public health agencies must still apply the processes of matching and merging information, and detecting and removing duplicate cases and reports, which adversely impacts the timeliness of disease trend analysis [4]. Thus, there is a need to modernize and enhance surveillance systems to detect the burden of disease and improve the targeting of prevention and control activities [2].

Although the internet is not a “new” technology, it is relatively new to the surveillance of infectious diseases. In 2004, Eysenbach coined the term “infodemiology” to describe the distribution of determinants of information on the internet and “infoveillance” to refer to syndromic surveillance of disease via the internet [5]. As the internet is a portal for free, asynchronous, and anonymously available health information, search engine data may provide an additional venue for surveillance efforts, thus leading to earlier detection of trends and increased ability to monitor impacts and regional geographic spread. Previous studies have examined the utility of Google Trends to monitor infectious diseases such as influenza, dengue, Lyme disease, and COVID-19 [6-9]. Search engine data have the potential to provide efficient and economical enhancement to the surveillance system established for STIs. Google Trends allows the download of deidentified search engine data trends, which can be used to investigate the implications of trends in STI-related search terms in relation to STI rates as well as facilitate disease nowcasting [10]. The term “nowcasting” refers to developing estimates of data in real time as the true data are being collected [11]. In reference to STIs, search engine data may provide the ability to determine trends in real time, which significantly enhances the current surveillance system [12]. This innovative tool has the potential to enable real-time surveillance of STIs, enhance understanding of changing STI trends, predict outbreaks, and increase the flexibility of the current system [3]. However, few studies, to

date, have used Google Trends to predict or forecast disease. In a 2018 review, only 8.7% (9/104) of studies using Google Trends for infodemiology included predictions or forecasting [13].

We build on our previous study, which found that Google search trend volume was positively and statistically significantly correlated with reported annual rates of STIs at the state level [12]. In this study, we develop and train a predictive model using reported STI morbidity data from the Chicago Department of Public Health (CDPH), and we investigate the predictive capacity, timeliness, and ability to target interventions using Google Trends data. Cook County, primarily encompassing Chicago, is a large, diverse jurisdiction with the second highest case counts (second to LA County, California) in the country for chlamydia, gonorrhea, and primary and secondary syphilis [2]. In conjunction with this high disease burden, Chicago has high internet penetration [14], making it a suitable city for testing our model [15].

Methods

A deidentified data set containing weekly STI case data for chlamydia, gonorrhea, and primary and secondary syphilis for 2011-2017 was obtained from the CDPH. The Institutional Review Board at the CDPH reviewed and approved the project proposal as exempt. Gonorrhea and primary and secondary syphilis have been nationally notifiable infections since 1944, and chlamydia, since 2010 [16]. The STI case data are aggregated to weekly counts for each case type (chlamydia, gonorrhea, and syphilis), with the date assigned based on the date the sample was obtained for testing. In addition to the STI diagnosis code, the data set includes race/ethnicity, age, and birth sex of the cases. Approximately 90% of all chlamydia and gonorrhea laboratory test results are reported via electronic laboratory reporting in real time via the Illinois National Electronic Disease Surveillance System. Data are deduplicated on a regular basis via built-in functionality or completed manually. All gonorrhea- and chlamydia-positive labs reported within >30 days are considered new cases. Reporting of syphilis cases is submitted electronically and managed manually. There were no specific STI city-wide prevention initiatives during the time period. The data are considered to be an accurate reflection of the rates of STIs in the city of Chicago [7].

The performance ability and predictive accuracy of the model rely on the selection of the search terms. To account for the breadth of terms that can possibly be used, the top 100 related search terms were obtained from Google Correlate using the initial term “std symptoms” [17]. All of the top 100 terms had correlation coefficients >0.85. After determining the related search terms, we established an autocrawler with Python [18] and used it to collect search volume data for each of the terms.

We used Google Health Application Programming Interface (API) (<https://trends.google.com/trends/>) data [19], which are a scaled proportion of the volume of all searches for all terms. The Google Health API results indicate the proportion of searches about the terms requested out of all searches that took place in Chicago per week for this time range, all multiplied by a consistent factor to increase ease of use. We excluded search

terms with an insufficient search volume (ie, incomplete or absent search trend results returned by Google). The retrieved search trend data were averaged on a weekly basis. None of the search data in this study contain personal information or individualized records of Internet search history.

The distributions of each of the STI case counts by week comprised non-negative count variables. We applied Poisson regression modelling as dictated by the outcome distribution and in consideration of the Google Trends data [10]. The primary equation of the model is $\log(\mu) = X_b$, where the response follows a Poisson distribution with parameters including mean μ . Coefficient vector b defines a linear combination X_b of the predictors X .

As the number of search query terms increases and exceeds the number of observations (in this case, the number of weeks), a curse-of-dimensionality and small- n -large- p affect the model. In addition, many of the query volumes may be zero because many queries are irrelevant (ie, assuming sparsity). Regularized regression schemes, such as lasso and elastic net, can solve this problem [11]. We used the elastic net penalty as it completes automatic variable selection and continuous shrinkage simultaneously, and it can select from a group of correlated variables, given the nature of correlated search queries [20].

We used a default parameter setting (10-fold cross validation for elastic net implementation in MATLAB 2017b to select the best regularization parameter lambda (λ) [21]. The queries selected for the best λ were used as the final set for the Poisson regression. We evaluated our approach for different values of ridge parameter α , starting from .5 to 1.0, and we chose the best

parameter value based on the highest correlation coefficient between the predicted and actual STI counts.

To estimate the potential time advantage of using the internet-based search terms, we applied cross-correlation analysis. Search terms were filtered by applying cross-correlation analysis to estimate the temporal relationship between the STI cases and Internet search volume derived from each term. The results were obtained as product-moment correlations between the 2 time series. The advantage of using cross-correlation is that it accounts for time dependence between 2 time series variables. The time dependence between 2 variables is termed as lag, which indicates the degree and direction of associations. A lag of -1 or $+1$ for assessing correlation implies that the Google Trend data have shifted backward or forward by 1 week from the CDPH data. Cross-correlation analysis also reduces spurious correlations in the subsequent regression analysis by excluding irrelevant Internet search trends. Those search terms that lacked statistically significant correlations or a definite time lag or lead pattern were excluded. We measured our performance by using the following metrics between the predicted and actual STI counts: Pearson correlation r and mean absolute error (MAE).

Results

Epidemiologic Overview

From 2011 to 2017, there were 170,368 reported cases of chlamydia, 65,224 reported cases of gonorrhea and 4278 reported cases of syphilis (Table 1).

Table 1. Demographic characteristics and number of laboratory-confirmed reported cases of chlamydia, gonorrhea, and syphilis by year for Chicago, IL.

Characteristics	Chlamydia, n (%)	Gonorrhea, n (%)	Syphilis, n (%)
Median age (years)	22	23	31
Sex, n (%)			
Male	66512 (33.63)	36282 (55.74)	2426 (74.39)
Female	131255 (66.36)	28800 (44.26)	835 (25.61)
Race, n (%)			
White	68687 (36.55)	20117 (31.82)	1965 (42.31)
Black	107631 (57.27)	41003 (64.86)	2246 (48.36)
Other	11594 (6.17)	2096 (3.31)	433 (9.32)
Cases by year, n (%)			
2011	27686 (75.07)	8533 (23.14)	658 (1.70)
2012	27729 (73.23)	9551 (25.224)	585 (1.50)
2013	27325 (74.18)	8889 (24.23)	618 (1.60)
2014	26990 (76.07)	7845 (22.11)	643 (1.80)
2015	28256 (76.67)	7840 (21.27)	758 (2.05)
2016	29776 (71.87)	10836 (26.15)	813 (1.96)
2017	30292 (70.75)	11730 (27.40)	788 (1.84)

Prediction

We evaluated the predictions of STI cases from the search terms for 5 consecutive annual periods from 2011 to 2017 using elastic net regression. Table 2 enumerates the performance results for the model for years 2011 to 2017. For gonorrhea and chlamydia, actual and predicted STI values correlated moderately in 2011 (chlamydia: $r=0.65$; gonorrhea: $r=0.72$) but correlated highly (chlamydia: $r=0.85-0.94$; gonorrhea: $r=0.82-0.90$) from 2012 to 2017. However, for primary and secondary syphilis, the high correlation was observed only for 2012 (0.79), 2013 (0.77), 2016 (0.80), and 2017 (0.84), with 2011, 2014, and 2015 showing moderate correlations (0.55-0.70). Though all the Pearson correlation coefficients were significant, MAE ranged

from 1.55%-3.02% for primary and secondary syphilis, 7.95%-19.04% for gonorrhea, and 17.04%-37.98% for chlamydia. Considering the high correlation in conjunction with the low MAE, the model performed the best for gonorrhea. Figures 1-3 present the graphical comparisons between the predicted and actual STI values for the year 2017 for gonorrhea, chlamydia, and syphilis. The search terms that appeared most frequently across all 3 diseases were “std symptoms in men,” “gonorrhea in men,” “yellow discharge,” “white creamy discharge,” “week pregnant,” and “white discharge.” All of the most common search terms relate to STI terminology, symptomology, or pregnancy (indicator of exposure to STI via condomless sex).

Table 2. Model prediction performance. $P < .001$ for all r values.

Year	Gonorrhea		Chlamydia		Primary and secondary syphilis	
	r	MAE ^a (%)	r	MAE (%)	r	MAE (%)
2011	0.72	12.56	0.65	36.12	0.70	2.50
2012	0.86	11.56	0.85	25.34	0.79	1.55
2013	0.88	19.04	0.94	37.98	0.77	2.24
2014	0.82	10.28	0.92	20.01	0.56	2.27
2015	0.85	8.27	0.87	23.27	0.55	3.02
2016	0.89	7.95	0.93	17.04	0.70	2.45
2017	0.90	10.23	0.91	22.26	0.79	1.94

^aMAE: Mean absolute error.

Figure 1. Graphical comparison between actual and predicted number of gonorrhea cases for 2017.

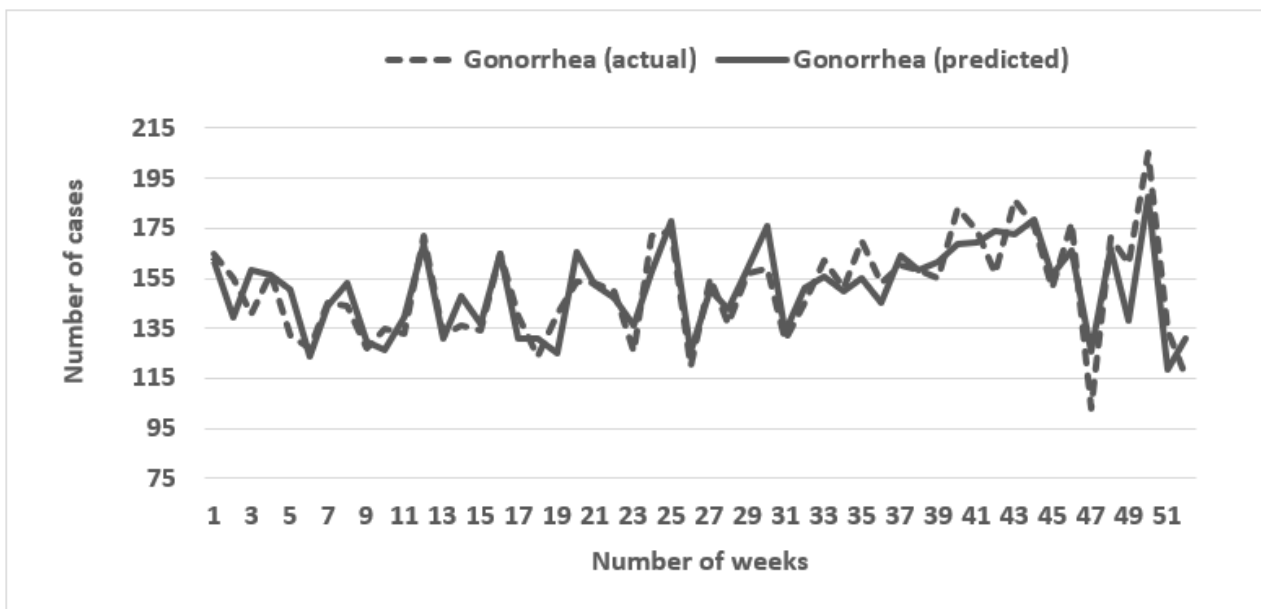
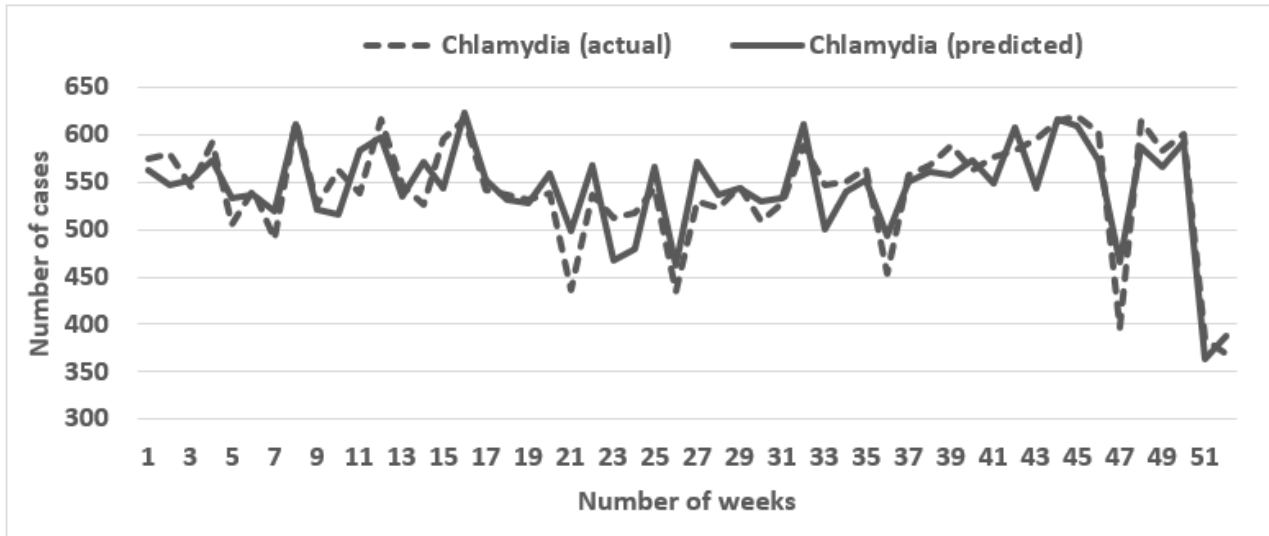
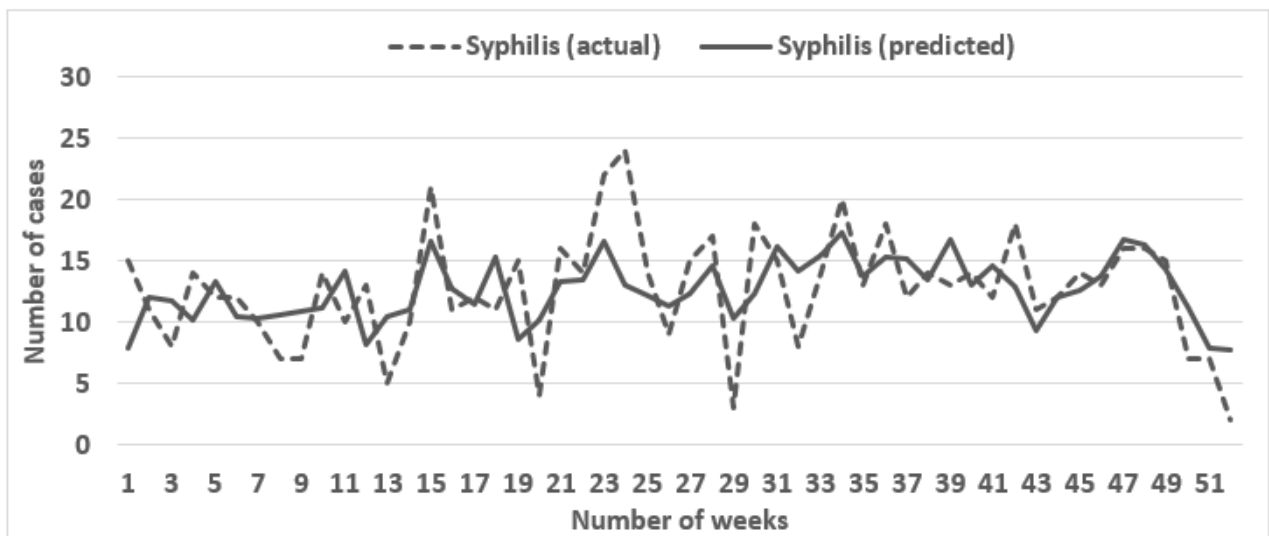


Figure 2. Graphical comparison between the actual and predicted number of chlamydia cases for 2017.**Figure 3.** Graphical comparison between the actual and predicted number of syphilis cases for 2017.

Subgroup Analyses

Following the same elastic net regression procedures, we developed separate models for the race (Black vs Nonblack), sex (male vs female), and age (<30 vs ≥30) subgroups. All the subgroup models across all years and all diseases (gonorrhea, chlamydia, and syphilis) performed optimally, showing high correlation values and low MAEs (see [Multimedia Appendix 1](#)). To illustrate performance, [Tables 3-5](#) provide the results of

elastic net regression for subgroup analyses for race, sex, and age for the gonorrhea case data for each year from 2011 to 2017. The subgroup models showed either similar or better performance than the full models across diseases and years: the correlations were high across subgroups of race, gender, and age (0.82-0.98), while the MAEs were low (2.67%-11.54%). The most frequent search terms for all 3 STIs for the category "Black" were "chlamydia treatment," "signs of STD," "smelly discharge," "can pregnant," and "creamy white discharge."

Table 3. Subgroup (race) prediction performance for gonorrhoea. $P<.001$ for all r values.

Year	Black		Nonblack	
	r	MAE ^a (%)	r	MAE (%)
2011	0.89	6.41	0.92	2.67
2012	0.85	8.81	0.89	3.70
2013	0.92	11.54	0.93	5.15
2014	0.82	6.22	0.85	6.56
2015	0.90	4.54	0.84	5.86
2016	0.84	5.49	0.93	1.94
2017	0.92	4.6	0.91	2.71

^aMAE: Mean absolute error.

Table 4. Subgroup (gender) prediction performance for gonorrhoea. $P<.001$ for all r values.

Year	Male		Female	
	r	MAE ^a (%)	r	MAE (%)
2011	0.88	4.73	0.92	2.67
2012	0.93	4.0	0.89	3.70
2013	0.96	5.25	0.93	5.15
2014	0.94	4.26	0.85	6.56
2015	0.93	3.94	0.84	5.86
2016	0.92	5.70	0.88	4.12
2017	0.91	6.13	0.90	3.92

^aMAE: Mean absolute error.

Table 5. Subgroup (age) prediction performance for gonorrhoea. $P<.001$ for all r values.

Year	Less than 30 years		30 years and above	
	r	MAE ^a (%)	r	MAE (%)
2011	0.83	9.15	0.81	3.17
2012	0.91	7.67	0.81	3.13
2013	0.97	7.59	0.86	4.42
2014	0.90	7.25	0.80	2.87
2015	0.98	2.30	0.87	2.78
2016	0.98	1.98	0.91	3.56
2017	0.91	7.22	0.83	3.92

^aMAE: Mean absolute error.

Cross-Correlation Analysis

First, we conducted a cross-correlation analysis to identify the temporal relationship between the STI data and search terms (ie, a lag or lead pattern). [Table 6](#) shows the results for chlamydia in the year 2017. The remaining results of the cross-correlation analysis on the search terms for each disease from 2012 to 2017 are included in [Multimedia Appendix 2](#). Trends for the search terms “feel pregnant” ($r=-0.28$, $P=.04$), “treatment for chlamydia” ($r=0.35$, $P=.01$), “std” ($r=-0.33$,

$P=.02$), “two weeks” ($r=0.28$, $P=.04$), “crabs std” ($r=-0.36$, $P=.02$), and “bleeding after period” ($r=-0.32$) coincided with the gonorrhoea data in 2015. Weekly case counts of gonorrhoea were preceded by 1 week by the trends of the following search terms: “does chlamydia” ($r=-0.34$, $P=.01$), “std symptoms in women” ($r=0.31$, $P=.02$), “gonorrhoea” ($r=-0.28$, $P=.04$), and “after period” ($r=-0.31$, $P=.02$). The trends of the following search terms were correlated with the case counts of gonorrhoea 1 week later: “wine while pregnant” ($r=0.29$, $P=.04$) and “talk to women” ($r=-0.30$, $P=.03$).

Table 6. Cross-correlation coefficients of reported cases of chlamydia using search term trend data for 2017^a.

Search terms	Lags (week)		
	-1	0	1
Internet search terms that preceded gonorrhoea case counts by 1 week			
does chlamydia	-0.34 ^b (<i>P</i> =.01)	0.01	0.001
std symptoms in women	-0.31 ^b (<i>P</i> =.02)	-0.04	0.16
gonorrhoea	-0.28 ^b (<i>P</i> =.04)	0.07	0.11
samuel l jackson movies	0.29 ^b (<i>P</i> =.04)	-0.18	0.04
after period	-0.31 ^b (<i>P</i> =.02)	0.09	-0.04
Internet search terms that coincided with gonorrhoea case counts			
treatment for chlamydia	0.00	-0.35 ^b (<i>P</i> =.01)	0.06
a black eye	-0.11	-0.28 ^b (<i>P</i> =.04)	0.12
std	0.09	0.33 ^b (<i>P</i> =.02)	0.12
two weeks	-0.04	0.28 ^b (<i>P</i> =.04)	0.08
crabs std	0.03	-0.36 ^b (<i>P</i> =.01)	0.003
feel pregnant	-0.12	-0.28 ^b (<i>P</i> =.04)	-0.15
bleeding after period	-0.09	-0.32 ^b (<i>P</i> =.02)	-0.005
Internet search terms that lagged gonorrhoea case counts by 1 week			
wine while pregnant	-0.10	-0.24	0.29 ^b (<i>P</i> =.04)
talk to women	-0.06	0.09	-0.30 ^b (<i>P</i> =.03)

^aOnly significant cross-correlation coefficient values are shown in this table.

^bValues indicate the maximum cross-correlation coefficient.

A separate regression analysis including only those search terms that coincided with and preceded the STI data by 2 weeks (ie, based on the results of the cross-correlation analysis in [Table 7](#)) was also conducted for recent years. The correlations between

the actual and predicted cases of gonorrhoea, chlamydia, and primary and secondary syphilis case counts are shown in [Table 7](#).

Table 7. Correlations between actual and predicted cases of STIs for 2015-2017. *P*<.001 for all *r* values.

Year	Gonorrhoea		Chlamydia		Primary and secondary syphilis	
	<i>r</i>	MAE ^a (%)	<i>r</i>	MAE (%)	<i>r</i>	MAE (%)
2015	0.60	12.35	0.66	32.22	0.59	2.94
2016	0.67	13.97	0.77	28.75	0.57	2.95
2017	0.46	21.49	0.65	37.98	0.52	2.71

^aMAE: mean absolute error.

Discussion

Findings

We performed a series of analyses to determine the predictive ability, timeliness, and performance of the Google Trends subgroups for the STI cases. The models performed consistently well overall across all diseases and time periods, showing moderate-to-high predictive power and low-to-moderate error. Applied nowcasting does not need to perform perfectly but must be reliable and consistent to inform disease control and response.

As illustrated by the analyses of the Google Trends for influenza surveillance, the predictive performance of search volume may vary by disease, location, and over time [22,23]. However, variability is to be expected, and uniform success is not necessary for application in a surveillance setting. Google Flu Trends operated from 2008 to August 2015 and showed varying accuracy for predicting real-time outbreaks of influenza using Google search terms [24]. Google Flu Trends demonstrated that internet-based search term surveillance should not be used as a standalone surveillance system due to the existence of temporal and geographic variability; however, traditional surveillance

systems could benefit by incorporating internet search term query data [24].

Our models were able to nowcast within a 1-week time frame, a substantial improvement from the delays observed when using traditional STI surveillance data. Further work is needed to determine thresholds for response, including determining what level of increase in case volume indicates a public health response and to what intensity. For example, a jurisdiction may decide that 10%, 20%, and 30% increases in search trend volumes may trigger a low intensity response (eg, provider awareness), public awareness, and active screening campaigns, respectively. Each of these thresholds and response activities need to be refined by local health departments based on epidemiologic trends and health department resources, but given the opportunity for real-time surveillance, and thus timely decision making and response provision, these efforts become urgent.

The ability to target prevention and control efforts to impacted subgroups is of great utility for public health efforts. Our model subgroup analyses performed better than or as efficiently as the aggregate models, demonstrating the ability to monitor trends in subgroups. These analyses were limited to the data available from our local health department; future studies should be conducted to refine and enhance subgroup performance. For example, control techniques may be influenced by outbreaks in specific neighborhoods; therefore, determining models fit for geographical subgroups (eg, community area and zip code) would be beneficial. Further, the analyses were conducted on retrospective data and involved using final cleaned surveillance data sets; future studies should be conducted prospectively in real time.

The search terms that most strongly correlated with the case counts for all 3 diseases were “std symptoms,” “gonorrhea in men,” “yellow discharge,” “white creamy discharge,” “week pregnant,” “yellow discharge,” and “white discharge.” All of these terms appear to be related to STI symptoms and are likely to be generated by those exposed to STIs (or cases). In a previous study, we established that those exposed to STIs are likely generating symptom-related search terms; we compared 2 different sexually active populations and found that compared to the student sample, a greater proportion of the clinical sample used the term “STD symptoms” or conducted symptom-related searches (47% vs 17%, $P < .01$) [17].

Google Trends supports credibility and transparency because these data are openly available, and our analyses are replicable by other investigators (see [Multimedia Appendix 3](#)). Further,

search volume data access via Google Trends has remained continuously available since 2008 [10]. This study only used 1 source of open data; future studies could incorporate multiple sources of open source data to determine if data triangulation improves performance.

An evaluation of 8 state-wide health systems in North Carolina compared International Classification of Diseases-9 codes to a broad range of reported cases of notifiable communicable diseases, and showed that completeness of reporting ranged from 0% to 82% depending on the particular disease [25]. Thus a heightened degree of underreporting may lead to increasing error when using a tool such as Google Trends to predict disease. Audits of diagnoses would be necessary to estimate the amount of underreporting and potentially account for this issue in analyses. We did not find audits of STI underreporting in the published literature; based on our experience in STI surveillance, we estimate that of the 3 STIs under surveillance, syphilis may be the least likely to be underreported due to greater awareness among providers, given the severity of its clinical presentation (eg, lesions, generalized body rash, and neurosyphilis) and relatively infrequency.

Limitations

The results of this study must be interpreted with the following limitations in mind. This study used STI case data from 1 jurisdiction in the United States; thus, it is unknown how nowcasting will function in other jurisdictions with different disease trends and search trend volumes. Future studies should include a representative selection of jurisdictions with high disease burdens and internet penetration. Our subgroup analysis was limited by the characteristics included in the STI case data available from the health department and did not include indicators such as zip code, community area, and socioeconomic status; therefore, we were not able to determine the impact of an analysis with these characteristics on target resources. Finally, our study used Google API, which is currently limited by Google to approved research institutions only, thus limiting the replication of the results to those who have API access.

Conclusion

This is the first study to examine the utility of Google Trends search volumes to predict STI cases at a city level. Future studies should replicate procedures for other US jurisdictions and prospectively examine model performance while developing tolerance levels for false positives. Integrating nowcasting with Google Trends in surveillance activities can potentially enhance the timeliness of outbreak detection and response.

Acknowledgments

This work was supported by a pilot grant awarded by the Northwestern University Clinical and Translational Sciences Institute (#UL1TR001422).

Conflicts of Interest

None declared.

Multimedia Appendix 1

Subgroup analysis.

[\[DOCX File, 20 KB - publichealth_v6i4e20588_app1.docx\]](#)

Multimedia Appendix 2

MATLAB code.

[\[TXT File, 2 KB - publichealth_v6i4e20588_app2.txt\]](#)

Multimedia Appendix 3

R code.

[\[TXT File, 1 KB - publichealth_v6i4e20588_app3.txt\]](#)**References**

- Centers for Disease Control and Prevention. Sexually Transmitted Disease Surveillance 2017. URL: <https://www.cdc.gov/std/stats17/default.htm> [accessed 2020-08-15]
- Centers for Disease Control and Prevention. Sexually Transmitted Disease Surveillance 2018. URL: <https://www.cdc.gov/std/stats18/default.htm> [accessed 2020-08-01]
- Van Beneden CA, Lynfield RU. Public health surveillance for infectious diseases. Principles and practice of public health surveillance. United Kingdom: Oxford University Press; 2010:236-254.
- Painter I, Revere D, Gibson PJ, Baseman J. Leveraging public health's participation in a Health Information Exchange to improve communicable disease reporting. *Online J Public Health Inform* 2017 Sep 08;9(2):e186 [FREE Full text] [doi: [10.5210/ojphi.v9i2.8001](https://doi.org/10.5210/ojphi.v9i2.8001)] [Medline: [29026452](https://pubmed.ncbi.nlm.nih.gov/29026452/)]
- Eysenbach G. Websites on screening for breast cancer: "infodemiology" studies have surely had their day. *BMJ* 2004 Mar 27;328(7442):769-770. [doi: [10.1136/bmj.328.7442.769-b](https://doi.org/10.1136/bmj.328.7442.769-b)] [Medline: [15044306](https://pubmed.ncbi.nlm.nih.gov/15044306/)]
- Sousa-Pinto B, Anto A, Czarlewski W, Anto JM, Fonseca JA, Bousquet J. Assessment of the impact of media coverage on COVID-19-related Google Trends data: Infodemiology study. *J Med Internet Res* 2020 Aug 10;22(8):e19611 [FREE Full text] [doi: [10.2196/19611](https://doi.org/10.2196/19611)] [Medline: [32530816](https://pubmed.ncbi.nlm.nih.gov/32530816/)]
- Samaras L, García-Barriocanal E, Sicilia M. Syndromic surveillance models using web data: The case of influenza in Greece and Italy using Google Trends. *JMIR Public Health Surveill* 2017 Nov 20;3(4):e90 [FREE Full text] [doi: [10.2196/publichealth.8015](https://doi.org/10.2196/publichealth.8015)] [Medline: [29158208](https://pubmed.ncbi.nlm.nih.gov/29158208/)]
- Syamsuddin M, Fakhruddin M, Sahetapy-Engel JTM, Soewono E. Causality analysis of Google Trends and dengue incidence in Bandung, Indonesia with linkage of digital data modeling: Longitudinal observational study. *J Med Internet Res* 2020 Jul 24;22(7):e17633 [FREE Full text] [doi: [10.2196/17633](https://doi.org/10.2196/17633)] [Medline: [32706682](https://pubmed.ncbi.nlm.nih.gov/32706682/)]
- Pesälä S, Virtanen MJ, Sane J, Mustonen P, Kaila M, Helve O. Health information-seeking patterns of the general public and indications for disease surveillance: Register-based study using lyme disease. *JMIR Public Health Surveill* 2017 Nov 06;3(4):e86 [FREE Full text] [doi: [10.2196/publichealth.8306](https://doi.org/10.2196/publichealth.8306)] [Medline: [29109071](https://pubmed.ncbi.nlm.nih.gov/29109071/)]
- Google. Trends Help. URL: <https://support.google.com/trends#topic=6248052> [accessed 2019-05-13]
- Lamos V, Miller AC, Crossan S, Stefansen C. Advances in nowcasting influenza-like illness rates using search query logs. *Sci Rep* 2015 Aug 03;5(1):12760 [FREE Full text] [doi: [10.1038/srep12760](https://doi.org/10.1038/srep12760)] [Medline: [26234783](https://pubmed.ncbi.nlm.nih.gov/26234783/)]
- Johnson AK, Mehta SD. A comparison of internet search trends and sexually transmitted infection rates using Google Trends. *Sexually Transmitted Diseases* 2014;41(1):61-63. [doi: [10.1097/olq.0000000000000065](https://doi.org/10.1097/olq.0000000000000065)]
- Mavragani A, Ochoa G, Tsgarakis KP. Assessing the methods, tools, and statistical approaches in Google Trends research: Systematic review. *J Med Internet Res* 2018 Nov 06;20(11):e270 [FREE Full text] [doi: [10.2196/jmir.9366](https://doi.org/10.2196/jmir.9366)] [Medline: [30401664](https://pubmed.ncbi.nlm.nih.gov/30401664/)]
- United States Census Bureau. American Community Survey (ACS). URL: <https://www.census.gov/programs-surveys/acs> [accessed 2020-08-15]
- Chicago Department of Public Health. HIV/STI Surveillance Report. 2017. URL: https://www.chicago.gov/content/dam/city/depts/cdph/HIV_STI/HIV_STISurveillanceReport2016_12012017.pdf [accessed 2020-10-09]
- Centers for Disease Control and Prevention. National Notifiable Diseases Surveillance System (NNDSS). URL: <https://www.cdc.gov/nndss/conditions/notifiable/2018/> [accessed 2020-08-14]
- Johnson AK, Mikati T, Mehta SD. Examining the themes of STD-related Internet searches to increase specificity of disease forecasting using Internet search terms. *Sci Rep* 2016 Nov 09;6(1):36503 [FREE Full text] [doi: [10.1038/srep36503](https://doi.org/10.1038/srep36503)] [Medline: [27827386](https://pubmed.ncbi.nlm.nih.gov/27827386/)]
- Rossum GV. The Python Language Reference. The Python Language Reference, Python Software Foundation 2018. [doi: [10.1201/9781584889304.axd](https://doi.org/10.1201/9781584889304.axd)]
- Google Trends. Explore what the world is searching. URL: <https://trends.google.com/trends/?geo=US> [accessed 2020-08-14]
- Zou H, Hastie T. Regularization and variable selection via the elastic net. *J Royal Statistical Soc B* 2005 Apr;67(2):301-320. [doi: [10.1111/j.1467-9868.2005.00503.x](https://doi.org/10.1111/j.1467-9868.2005.00503.x)]

21. Grant M, Boyd S, Ye Y. MATLAB software for disciplined convex programming. In: Nonconvex Optimization and Its Applications. Switzerland: Springer Link; 2009:155-210.
22. Carneiro H, Mylonakis E. Google trends: a web-based tool for real-time surveillance of disease outbreaks. Clin Infect Dis 2009 Nov 15;49(10):1557-1564. [doi: [10.1086/630200](https://doi.org/10.1086/630200)] [Medline: [19845471](https://pubmed.ncbi.nlm.nih.gov/19845471/)]
23. Preis T, Moat HS. Adaptive nowcasting of influenza outbreaks using Google searches. R Soc Open Sci 2014 Oct;1(2):140095. [doi: [10.1098/rsos.140095](https://doi.org/10.1098/rsos.140095)] [Medline: [26064532](https://pubmed.ncbi.nlm.nih.gov/26064532/)]
24. Klembczyk JJ, Jalalpour M, Levin S, Washington RE, Pines JM, Rothman RE, et al. Google flu trends spatial variability validated against emergency department influenza-related visits. J Med Internet Res 2016 Jun 28;18(6):e175 [FREE Full text] [doi: [10.2196/jmir.5585](https://doi.org/10.2196/jmir.5585)] [Medline: [27354313](https://pubmed.ncbi.nlm.nih.gov/27354313/)]
25. Sickbert-Bennett EE, Weber DJ, Poole C, MacDonald PD, Maillard J. Completeness of communicable disease reporting, North Carolina, USA, 1995–1997 and 2000–2006. Emerg. Infect. Dis 2011 Jan;17(1):23-29. [doi: [10.3201/eid1701.100660](https://doi.org/10.3201/eid1701.100660)]

Abbreviations

- API:** application programming interface
CDPH: Chicago Department of Public Health
MAE: mean absolute error
STI: sexually transmitted infection

Edited by G Eysenbach; submitted 22.05.20; peer-reviewed by KA Nguyen, J Soriano; comments to author 06.07.20; revised version received 26.08.20; accepted 01.09.20; published 05.11.20.

Please cite as:

Johnson AK, Bhaumik R, Tabidze I, Mehta SD

Nowcasting Sexually Transmitted Infections in Chicago: Predictive Modeling and Evaluation Study Using Google Trends

JMIR Public Health Surveill 2020;6(4):e20588

URL: <http://publichealth.jmir.org/2020/4/e20588/>

doi: [10.2196/20588](https://doi.org/10.2196/20588)

PMID: [33151162](https://pubmed.ncbi.nlm.nih.gov/33151162/)

©Amy Kristen Johnson, Runa Bhaumik, Irina Tabidze, Supriya D Mehta. Originally published in JMIR Public Health and Surveillance (<http://publichealth.jmir.org>), 05.11.2020. This is an open-access article distributed under the terms of the Creative Commons Attribution License (<https://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in JMIR Public Health and Surveillance, is properly cited. The complete bibliographic information, a link to the original publication on <http://publichealth.jmir.org>, as well as this copyright and license information must be included.

Review

Social Media as a Research Tool (SMaaRT) for Risky Behavior Analytics: Methodological Review

Tavleen Singh¹, MS; Kirk Roberts¹, PhD; Trevor Cohen², MBChB, PhD; Nathan Cobb³, MD; Jing Wang⁴, RNC, MPH, PhD, FAAN; Kayo Fujimoto⁵, PhD; Sahiti Myneni¹, MSE, PhD

¹School of Biomedical Informatics, The University of Texas Health Science Center, Houston, TX, United States

²Biomedical Informatics and Medical Education, University of Washington, Seattle, WA, United States

³Georgetown University Medical Center, Washington, DC, United States

⁴School of Nursing, The University of Texas Health Science Center, San Antonio, TX, United States

⁵School of Public Health, The University of Texas Health Science Center, Houston, TX, United States

Corresponding Author:

Tavleen Singh, MS
School of Biomedical Informatics
The University of Texas Health Science Center
7000 Fannin Street
Suite 600
Houston, TX, 77030
United States
Phone: 1 713 500 3900
Email: tavleen.kaur.ranjit.singh@uth.tmc.edu

Abstract

Background: Modifiable risky health behaviors, such as tobacco use, excessive alcohol use, being overweight, lack of physical activity, and unhealthy eating habits, are some of the major factors for developing chronic health conditions. Social media platforms have become indispensable means of communication in the digital era. They provide an opportunity for individuals to express themselves, as well as share their health-related concerns with peers and health care providers, with respect to risky behaviors. Such peer interactions can be utilized as valuable data sources to better understand inter- and intrapersonal psychosocial mediators and the mechanisms of social influence that drive behavior change.

Objective: The objective of this review is to summarize computational and quantitative techniques facilitating the analysis of data generated through peer interactions pertaining to risky health behaviors on social media platforms.

Methods: We performed a systematic review of the literature in September 2020 by searching three databases—PubMed, Web of Science, and Scopus—using relevant keywords, such as “social media,” “online health communities,” “machine learning,” “data mining,” etc. The reporting of the studies was directed by the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) guidelines. Two reviewers independently assessed the eligibility of studies based on the inclusion and exclusion criteria. We extracted the required information from the selected studies.

Results: The initial search returned a total of 1554 studies, and after careful analysis of titles, abstracts, and full texts, a total of 64 studies were included in this review. We extracted the following key characteristics from all of the studies: social media platform used for conducting the study, risky health behavior studied, the number of posts analyzed, study focus, key methodological functions and tools used for data analysis, evaluation metrics used, and summary of the key findings. The most commonly used social media platform was Twitter, followed by Facebook, QuitNet, and Reddit. The most commonly studied risky health behavior was nicotine use, followed by drug or substance abuse and alcohol use. Various supervised and unsupervised machine learning approaches were used for analyzing textual data generated from online peer interactions. Few studies utilized deep learning methods for analyzing textual data as well as image or video data. Social network analysis was also performed, as reported in some studies.

Conclusions: Our review consolidates the methodological underpinnings for analyzing risky health behaviors and has enhanced our understanding of how social media can be leveraged for nuanced behavioral modeling and representation. The knowledge gained from our review can serve as a foundational component for the development of persuasive health communication and effective behavior modification technologies aimed at the individual and population levels.

KEYWORDS

social media; infodemiology; infoveillance; online health communities; risky health behaviors; data mining; machine learning; natural language processing; text mining

Introduction

Modifiable risky health behaviors, such as tobacco use, excessive alcohol use, being overweight, lack of physical activity, and unhealthy eating habits, are some of the major factors for developing chronic health conditions [1]. Chronic health conditions, such as cancer and heart disease, lead to approximately 1.5 million deaths per year in the United States [2]. These chronic health conditions together with diabetes are also responsible for nearly US \$3.5 trillion in annual economic costs; hence, it becomes crucial to prevent and/or efficiently manage such conditions [2]. Behavior modification is pivotal for managing chronic health conditions, and a range of psychological and social processes have been shown to influence the engagement of an individual in the adoption of positive healthy behaviors [3,4]. Traditionally, the methods used for measuring and studying health-related behaviors in populations include telephone or internet-based surveys [5], motivational interviews [6], commercial wearables and smartphone apps [7], and ecological momentary assessment [8].

Recently, social media has emerged as a viable platform for studying and analyzing health-related behaviors and promoting behavior change [9]. The field of infodemiology [10] examines the determinants and distribution of health information in the electronic medium (eg, social media and internet) for public health purposes: preventing diseases via predictive modeling [11-13], informing policy regulations [14], assessing the quality of health information on websites [15], and analyzing the health-related behaviors of individuals [16-18]. The recent COVID-19 pandemic has also shown how analyzing communication on such platforms can provide insights into the attitudes and behaviors of individuals as well as health care providers [19,20].

Social media, through its various mobile and web-based technologies, provides interactive platforms for individuals and communities to share, create, modify, and discuss content in the form of ideas, messages, or information [21]. In recent years, the penetration of social media platforms has increased in all spheres of life. According to the Global Digital Report of 2019, there are about 3.5 billion active social media users throughout the world, with Facebook being the most dominant social networking website. More than two-thirds of the world's population use a mobile device, mostly a smartphone. Powered by these connected devices, many older adults as well as teenagers have also started incorporating social media into their daily routines [22].

Consequently, social media has become an important part of the public health landscape, given that these platforms are increasingly being used by health care consumers for gaining knowledge on a variety of health-related topics as well as for interacting with their peers and health care providers to garner

social support, mostly informational and emotional in nature [23,24]. These platforms are widely used by health care consumers to (1) meet their health-related goals [25] and (2) adopt positive health behaviors [26,27]. Research has shown that an individual is more likely to comply with health-related goals and adhere to preventive practices provided their social ties also engage in similar behaviors [28,29]. The major advantages of using such platforms over standard approaches for studying and analyzing health promotion and behavior change include their ability to reach a wider and less accessible audience, cost-effective recruitment of participants for research, and their round-the-clock accessibility via mobile and web-based connections [30]. These platforms can leverage group norms; thus, behavior change interventions implemented through these platforms have the potential to make a significant impact through widespread diffusion of preventive programs to meet the needs of individuals, communities, and populations.

These online platforms can be broadly classified into two major categories: (1) open social media platforms (eg, Facebook, Twitter, and Reddit), which are generic platforms used for networking, information sharing, and collaboration, and (2) intentionally designed health-related social media platforms (eg, QuitNet [31] and BecomeAnEX.org [32]), which focus on providing health-specific support to its members. Even though open social media platforms provide opportunities for large-scale inferences about behaviors of individuals, they still lack in providing context-specific interactional observations, for which we need to turn to intentionally designed social media platforms [33]. Depending on whether or not a social media platform has a specific focus on health topics, the environmental factors affecting an individual's attempt to sustain positive health changes can greatly vary, thus affecting contextual granularities that inform the accuracy and reliability of computational and quantitative data modeling approaches. Despite these differences, the universal presence of these platforms has led to the generation of invaluable and large data sets in the form of electronic traces of peer interactions in the form of text, images, or videos (eg, traditional forums like Facebook and YouTube). These data sets capture the attitudes and behaviors of individuals in near real time and in natural settings as compared to conventional settings, which involve the presence of a researcher and are prone to instrument bias [34]. The analysis of such data sets provides us with an opportunity to understand the individualistic as well as environmental factors underlying behavior change, which can eventually guide the design and development of network interventions for health-related behavior change [35-37].

Traditional methods of qualitative data analysis are not conducive to analyzing large amounts of data generated by social media platforms. Recent advances in automated text analysis provide us with suitable methods for analyzing digital content generated from social media platforms. The latest review

highlights the breakthroughs in computational technologies that are currently being applied to the field of health care in the form of digitized data acquisition, machine learning (ML) techniques, and computing infrastructure [38]. In addition to advances in predictive analytics and combinatorial forces from mobile computing and the internet, participatory social media has resulted in rich, just-in-time data that can be leveraged to conduct digital phenotyping of health consumer engagement in self-management of risky health behaviors.

The objective of this review is to summarize computational and quantitative approaches that highlight the potential of using social media as a research tool (SMaaRT) to understand the patterns of inter- and intrapersonal psychosocial factors associated with the prevention and management of risky health behaviors. These methodologies can provide a comprehensive understanding of the most common practices, their utility, limitations, and resulting inferences, thus providing health researchers with capabilities to better describe health behaviors at scale. The enhanced understanding from these secondary analyses can ultimately be infused into the design processes of effective behavioral interventions through the translation of data-driven insights into practical public health solutions via scalable techniques, such as tailored messaging and persuasive environment design.

Methods

Overview

We conducted a systematic review of the literature to summarize the computational and quantitative methods for analyzing social

media data that have been used to study risky health behaviors. We followed the guidelines outlined by PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) [39] to retrieve relevant studies.

Literature Search Strategy

We searched the literature in September 2020, collecting studies published between 2011 and September 11, 2020. We searched three different databases—PubMed, Web of Science, and Scopus—using a specific set of keywords. Our search keywords lie at the intersection of two key clusters: social media and ML. We also included Medical Subject Headings (MeSH) for relevant keywords to ensure our search was as inclusive as possible. The search was conducted using the following query: (“Social Media” [MeSH] OR “social media” OR “Online Health Community” OR “Online Health Communities” OR “Online Social Network” OR “Online Social Networks” OR “peer to peer” OR “Peer Influence” [MeSH]) AND (“Machine Learning” [MeSH] OR “machine learning” OR “text mining” OR “Natural Language Processing” [MeSH] OR “natural language processing” OR “Data Mining” [MeSH] OR “data mining” OR “network models”). In addition, we also examined the reference lists of studies that met our inclusion criteria for any additional sources.

Inclusion and Exclusion Criteria

The inclusion and exclusion criteria to determine eligibility of studies for the review are listed in [Textbox 1](#).

Textbox 1. Eligibility criteria for the studies.

Inclusion criteria:

1. Studies conducted original research that was published in a peer-reviewed journal.
2. Studies used English language–based social media platforms (ie, the language of generated content is in the English language).
3. Studies conducted data analysis at scale using computational or quantitative methods like machine learning techniques, network modeling, and/or visualization techniques.
4. Studies focused on risky health behaviors, or related attitudes or beliefs, of the patients or health consumers such as nicotine use, alcohol use, drug or substance abuse, physical activity or inactivity patterns, or obesity-related behaviors.
5. Studies focused primarily on analyzing textual content from online social media platforms (eg, YouTube comments instead of YouTube videos).

Exclusion criteria:

1. Studies described the use of social media platforms for other purposes (eg, recruitment and data collection).
2. Studies focused on health care providers instead of patients or health consumers.
3. Studies focused on behaviors unrelated to health.

Data Extraction

Two authors (TS and SM) independently assessed the retrieved studies against the inclusion criteria in two stages. In the first stage, the authors reviewed the titles and abstracts of all the retrieved studies for their inclusion in full-text screening. In the second stage, the authors performed the full-text screening of the relevant studies identified from the first stage for final inclusion in this review. Disagreements were resolved through

discussion between the two authors. The interrater agreement, Cohen κ , was calculated at both stages. After screening the studies that met our inclusion criteria, we extracted the relevant data from the main text, which included the following:

1. Risky health behavior studied, such as nicotine use, alcohol use, drug or substance abuse, physical activity or inactivity patterns, obesity-related behaviors, etc.
2. Social media platform used for the study, whether it was an open social network, such as Twitter or Facebook, or a

- disease-specific social network, such as QuitNet (ie, smoking cessation).
- Number of posts: total number of posts used for analysis and number of posts used for manual annotations.
 - Study focus: what were the underlying aims of the study for analyzing risky health behaviors?
 - Key methodological functions and tools; for example, topic modeling (ie, function) was performed using latent Dirichlet allocation (LDA) (ie, method).
 - Evaluation metrics used by the study (eg, precision, recall, and F1 score).
 - Key findings of the study: results obtained after analyzing the data generated from online peer interactions.

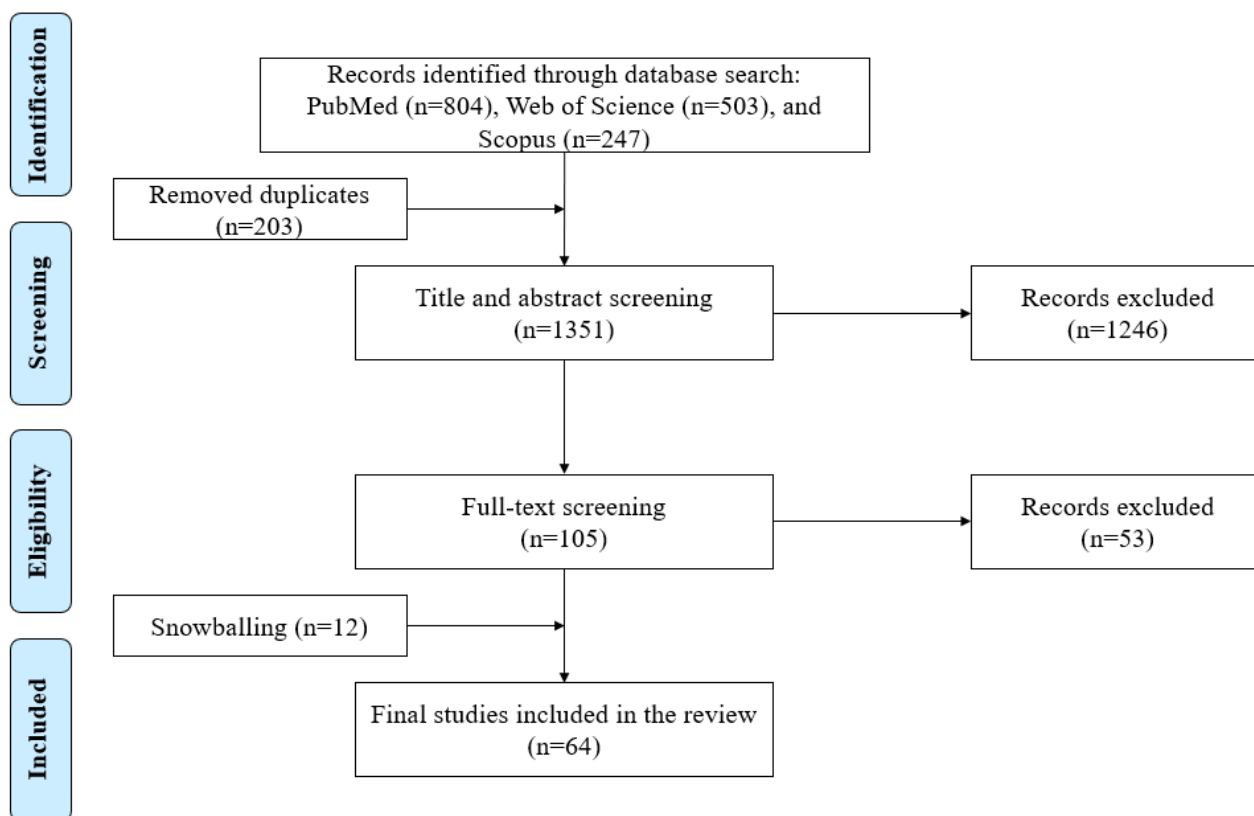
Results

Overview

The initial search resulted in a total of 1554 studies. From these, we removed 203 studies because of duplication. In the first

stage, we reviewed the titles and abstracts of the remaining studies to ensure that they met the inclusion and exclusion criteria for further thorough analysis. The interrater agreement at the first stage was 81.37%. After resolving disagreements through discussion, we initially excluded 1246 studies that did not meet the inclusion criteria and included the remaining 105 studies for full-text screening in the second stage. The interrater agreement at the second stage was 83.50%. A total of 52 studies meeting the inclusion criteria were included in the review. We further identified 12 additional studies through the snowballing technique that were also included in this review. Thus, a total of 64 studies [40-103] were included in the final review. Of the studies reviewed, 55 (86%) studies were published from 2016 onward [40-61,68-95,97,98,100-102], while only 9 (14%) studies were published between 2013 and 2015 [62-67,96,99,103]. None of the studies were published before 2013. Figure 1 shows the PRISMA diagram highlighting the overall process of selecting the final studies for the review.

Figure 1. PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) diagram for study selection.



The results of our review showed that the focus of social media analysis has been on a variety of risky health behaviors, including nicotine use, alcohol use, drug abuse, physical activity patterns, and obesity-related behaviors. Social media platforms have been widely used for secondary data analysis as well as for follow-up analysis of data generated from active interventions or campaigns conducted using such platforms. Multiple computational and quantitative functions and tools were utilized for analyzing the data generated from online peer interactions on social media platforms. A detailed exposition of our results is included in [Multimedia Appendix 1](#), which

shows the key characteristics of the selected studies grouped by risky health behaviors and then ordered by year published.

In the following sections, we aggregate the results of our review to highlight the usage patterns of various social media platforms for secondary analysis purposes, the prevalence of risky health behaviors studied on these platforms, and the methodological tools and functions used to understand these behaviors.

Social Media Platforms

[Table 1](#) [40-103] highlights the social media platforms used for analyzing risky health behaviors. Twitter (39/64, 61%) appeared

to be the most widely utilized social media platform for analyzing online peer interactions regarding risky health behaviors, followed by Facebook (6/64, 9%), QuitNet (5/64, 8%), Reddit (5/64, 8%), BecomeAnEx.org (3/64, 5%), Instagram (2/64, 3%), Cancer Survivors Network (1/64, 2%), Hello Sunday Morning blog (1/64, 2%), patient.info/forums (1/64, 2%), and a peer-to-peer online discussion forum, which is part of a smartphone app called Addiction–Comprehensive Health Enhancement Support System (A-CHESS) (1/64, 2%). Out of 64 studies, 1 (2%) analyzed the data from three online forums: Vapor Talk, Hookah Forum, and Stopsmoking subreddit [62]. A total of 80% (51/64) of the studies utilized open social media platforms, such as Twitter, Facebook, Instagram, and Reddit [40–44,47–54,58–61,63,66–83,85,87,88,92–103], while the remaining 20% (13/64) of the studies utilized specific health-related online social networks, such as QuitNet, BecomeAnEX.org, Cancer Survivors Network, patient.info/forums, Hello Sunday Morning blog, and A-CHESS online discussion forum [45,46,55–57,62,64,65,84,86,89–91].

Most of the studies that used Twitter as their data source relied on Twitter application programming interfaces (APIs) for

extracting the data. The majority of these studies utilized streaming APIs, which provide a push of the subset of data in near real time [47,50,51,59,61,70,74,78–81,92,94,95], and some of these studies also used search APIs, which provide access to the data set that consists of tweets that have already occurred in the past [68,76,82,98,99]. Some studies also used Twitter's data provider called Gnip [54,59,60,63,92], which guarantees access to all the tweets that match the researcher's criteria. Some studies did not indicate which specific kind of API was used for accessing Twitter's data [40,41,48,66,73,77,88,100,102]. For Reddit, the data were extracted using the following techniques: (1) the use of Pushshift, which is a publicly available archive of Reddit submissions [42], (2) the data set was downloaded using a web crawler called Wget [62], (3) the use of Python Reddit API Wrapper [97], (4) the data set was released from the Reddit member [101], and (5) the use of Reddit's official API [103]. The data from Facebook were extracted using either Facebook's API and the Facebook platform's Python software development kit [87] or by using the extraction feature in NVivo (QSR International) [71]. A similar approach was used for extracting data using Instagram's API [44,72].

Table 1. Social media platforms used by various studies.

Social media platforms	Number of studies (N=64), n (%) ^a	Study references
Twitter	39 (61)	[40,41,43,47, 48,50–52, 54,58–61, 63,66–70,73–83, 88,92,94–96,98–100,102]
Facebook	6 (9)	[49,53,71,85,87,93]
QuitNet	5 (8)	[45,55,56,64,65]
Reddit	5 (8)	[42,62,97,101,103]
BecomeAnEX.org	3 (5)	[46,86,91]
Instagram	2 (3)	[44,72]
Hello Sunday Morning blog	1 (2)	[90]
A-CHESS ^b (online discussion forum)	1 (2)	[89]
Cancer Survivors Network	1 (2)	[57]
Patient.info/forums	1 (2)	[84]
Vapor Talk, Hookah Forum, and Stopsmoking subreddit	1 (2)	[62]

^aPercentages do not add up to 100% due to rounding and one study that used multiple social media platforms.

^bA-CHESS: Addiction–Comprehensive Health Enhancement Support System.

Risky Health Behaviors

Table 2 [40–103] highlights the risky health behaviors studied and the associated social media platforms leveraged for conducting the study. The most commonly studied risky health behavior on social media platforms was related to the use of nicotine products, with a total of 28 out of 64 (44%) studies [40–67] focusing on behaviors related to smoking, e-cigarettes, little cigars, etc. Twitter (16/64, 25%) was widely used for analyzing such behaviors, followed by QuitNet (5/64, 8%), Facebook (2/64, 3%), Reddit (1/64, 2%), Instagram (1/64, 2%), Cancer Survivors Network (1/64, 2%), BecomeAnEX.org (1/64, 2%), and Vapor Talk, Hookah Forum, and Stopsmoking subreddit (1/64, 2%). The majority of these studies were focused on analyzing members' behavior or sentiment toward smoking

products, such as e-cigarettes [42,49,50,52,54,58,59,61–63], hookah products [43,47,51,62], JUUL or vaping [40,41,44], and cigars [60], or analyzing sentiments toward smoking in general [67]. Out of 64 studies, 2 (3%) focused primarily on social network analysis: one to understand how the structure of social networks influence the smoking behaviors of the members of the community [53], and the other to understand the reach of an antismoking campaign targeting young individuals [48]. Other studies focused on (1) analyzing member-generated content to derive common themes or topics of discussions among peers [57,64–66], (2) characterizing behavioral transitions during smoking cessation [45], (3) studying temporal trends of peer interactions to gain insights into factors underlying smoking

cessation behavior change [55,56], and (4) predicting smoking status [46].

Drug or substance abuse was another commonly discussed risky health behavior on social media platforms, with a total of 14 out of 64 (22%) studies discussing the topic [68-81]. Twitter (12/64, 19%) again was the most popular platform for studying drug or substance abuse behaviors, followed by Instagram (1/64, 2%) and Facebook (1/64, 2%). The focus areas for these studies included prescription drug abuse [68,70,78,81], opioid misuse [74-77], cannabis and synthetic cannabinoid use [80], and substance or drug abuse [69,71-73]. One study analyzed multiple behaviors related to substance abuse, which included alcohol, smoking, and drug use [79].

Out of 64 studies, 12 (19%) explored the alcohol usage patterns and abstinence behaviors among members of online health communities [82-93]. Some of these studies (1) conducted a thematic analysis of alcohol-related content generated from an online smoking cessation community [86,91], (2) focused on analyzing trends of alcohol use behavioral stages [92], (3) analyzed binge-drinking behaviors [82,83,87], (4) focused on extracting topics and sentiments related to alcohol use

[84,85,93], and (5) focused on predicting future relapse or recovery alcoholism [88,89]. One study analyzed the content of a blog that encouraged its members to stop drinking for a specific period of time and discuss their progress with their peers [90]. The distribution of platforms used for analyzing alcohol use behaviors was quite variable (see Table 2 [40-103]).

Out of 64 studies, 3 (5%) explored the patterns and types of physical activity engagement among members of the community [94-96]. All of these studies were conducted using Twitter as their source of data. Out of 64 studies, 3 (5%) analyzed topics and themes related to obesity-related behaviors [97-99] using social media platforms, such as Twitter and Reddit. There were 4 out of 64 (6%) studies [100-103] that studied multiple behaviors together, such as (1) analyzing obesity and physical activity-related content in order to get information about the health status of individuals [100], (2) identifying topics of discussion related to e-cigarettes and marijuana use [101], and (3) characterizing tobacco- and alcohol-related behavioral patterns [102,103]. Out of these 4 studies, 2 (50%) utilized Twitter [100,102] and 2 (50%) utilized Reddit [101,103] as their data source.

Table 2. Risky health behaviors and their associated social media platforms.

Risky health behaviors	Number of studies (N=64), n (%) ^a	Social media platforms and study references
Nicotine use	28 (44)	Twitter [40,41,43,47,48,50-52,54,58-61,63,66,67] QuitNet [45,55,56,64,65] Facebook [49,53] Reddit [42] Instagram [44] Cancer Survivors Network [57] BecomeAnEX.org [46] Vapor Talk, Hookah Forum, and Stopsmoking subreddit [62]
Drug and substance abuse	14 (22)	Twitter [68-70,73-81] Instagram [72] Facebook [71]
Alcohol use	12 (19)	Twitter [82,83,88,92] Facebook [85,87,93] Patient.info/forums [84] BecomeAnEX.org [86,91] A-CHESS ^b online discussion forum [89] Hello Sunday Morning blog [90]
Physical activity	3 (5)	Twitter [94-96]
Obesity-related behaviors	3 (5)	Reddit [97] Twitter [98,99]
Multiple behaviors (ie, e-cigarettes and marijuana, smoking and drinking, and physical activity and obesity-related behaviors)	4 (6)	Twitter [100,102] Reddit [101,103]

^aPercentages do not add up to 100 due to rounding.

^bA-CHESS: Addiction-Comprehensive Health Enhancement Support System.

Methodological Details and Related Tools

The methodological functions used across various studies are discussed in the following sections, as well as the specific tools used for performing those functions.

Computational Modeling: Feature Extraction

The most commonly extracted features were n-grams (eg, unigrams, bigrams, and trigrams) [40,44,46,47,58,59, 63,66, 67, 70,74, 75, 80-82,86, 91,92,96, 99,100,102,103]. In addition to that, some studies also made use of additional features like count vectors [41], term frequency-inverse document frequency vectors [41,63,80,82,86,87,91,92,100], language-based covariates [42], number of hashtags [44], number of hashtags containing specific strings [44], usernames [44], part of speech tags [59], sentiment scores [59,68], presence of specific terms in usernames [59], domain-specific features [46], Doc2Vec features [46], author-based features [46], thread-based features [46], user metadata features [54,82,86,92], derived behavior features (eg, unique keyword count in original tweets, unique keyword count in hashtags in original tweets, etc) [54], personal noun [68], nonmedical use terms [68], medical use terms [68], side-effect terms [68], presence of a URL [68], abuse indication terms [73-75,81], drug-slang lexicon [73,81], synonym expansion features using WordNet [73,81], word cluster features [73-75,81], features based on behavior coping styles [88], social factors [88], age [88], and image-based features [72]. Some studies used feature selection techniques, such as SelectKBest [40], information gain [66], and the chi-square test [80]. One study performed evaluation of relevant features for each classifier using a technique called SHAP (SHapley Additive exPlanations) [41].

Computational Modeling: Classification Techniques

Traditional ML Classifiers

Most of the studies utilized supervised ML classifiers for text analysis to perform either predictive modeling, behavioral stage modeling, or content analysis. The classifiers used across various studies included support vector machine (SVM) [51,54,66,67,70,73-75,80-82,92,94,100,102], SVM (linear) [41,44,45,58,60,63,87,102], SVM (radial kernel) [44,68,87], SVM (polynomial kernel) [46,87], SVM (sigmoid) [87], logistic regression (LR) [40,41,44-46,54,58-60,72,80,89,92,94,100,102], naïve Bayes [40,41,46, 52,54,58, 60,63,66, 70,73-75, 80,81,86, 91, 100], random forest (RF) [40,41,45,54,58,70,73-75,82,84,86,91,92,100,102], decision tree-based classifier (DT) (eg, J48) [46,54,55,74,81,86,91], k-nearest neighbors (KNN) [54,63,66,74,84], AdaBoost [46,54,86,91], maximum entropy text classifier [79,81,94,95], sequential minimal optimization [84], multilayer perceptron [84], REPTree [88], feed-forward neural network [94], and gradient boosting [48,54,94]. One study used a supervised version of LDA called labeled LDA for text classification [87], while another utilized a supervised learning-based statistical model called the ridge regression statistical model for performing the classification task [103]. One study developed a text mining framework to evaluate data quality using a search query-based classifier and an evaluation matrix-based classifier

[69]. One study used RtextTools in R (The R Foundation) for automated text classification via supervised learning [43].

One study utilized specialized software for analyzing textual content generated from online peer interactions, namely, Leximancer [90]. Few studies used packages in R for text mining, such as RWeka [43] and tm [43,68,98,99].

Deep Learning Techniques

Out of 64 studies, 6 (9%) used deep learning models for text classification, such as convolutional neural networks (CNNs) [41,70,73-75,100], long short-term memory (LSTM) [41,72], LSTM-CNN [41], bidirectional LSTM [41], shallow neural network [100], and reinforcement neural network-gated recurrent unit [100]. Hassanpour et al [72] optimized their deep learning model through the stochastic gradient descent optimization algorithm. One study used an ensemble deep learning model consisting of a word-level CNN and a character-level CNN [73]. One of these studies also performed image classification using image features extracted through a residual neural network [72], which is a state-of-the-art CNN architecture for computer vision tasks. Another study [87] performed image as well as video classification using a neural network called AlexNet, which is another famous deep CNN used for computer vision problems.

Word Embeddings: Pretraining

The following studies used pretraining with word embeddings, such as global vectors (GloVe) word vectors (ie, general domain) [41], word2vec pretrained on the Wikipedia corpus [72], and word2vec pretrained using domain-specific corpora [41,70,74,75]. One study pretrained with the image classifier model using the ImageNet data repository [72], and in another study a word-level CNN was pretrained on drug chatter word embeddings (ie, 400 dimensions) [73].

Empirical Distributional Semantics

Some studies applied distributional semantics to recognize meaningful relationships between terms, for instance, between messages and identified themes applying techniques such as latent semantic analysis (LSA) [64,65], random indexing (RI) [55], and the skip-gram with negative sampling (SGNS) algorithm [56] using the Semantic Vectors package. Some of these studies used pretraining on general domain corpora: RI with the Touchstone Applied Science Associates (TASA) corpus [55], the SGNS algorithm with the Wiki corpus [56], and LSA with the TASA corpus [64,65].

Topic Modeling

Multiple techniques were used for topic modeling, such as Quanteda software [42], LDA [49, 57,60,62, 69,77,83, 84,97-99, 101], SAS Text Miner (SAS Institute) [61,76,85,93], and correlated topic modeling, using the topicmodels package in R [86]. Out of 64 studies, 2 (3%) used the word2vec model: one to identify words similar to unigrams and bigrams per topic [47] and another for word semantic clustering [97]. One study detected topics by calculating frequency vectors to create a term-Tweet frequency table and performed chi-square tests to compare terms across the corpus [96].

Various unsupervised ML models were also utilized for identifying e-cigarette communities using k-means clustering [42] and pattern or theme recognition through a technique called the biterm topic model [78]. One study performed clustering analysis through an agglomerative hierarchical clustering technique [102] to group the temporal patterns of alcohol consumption among members of an online community.

Language Modeling

Out of 64 studies, 5 (8%) performed linguistic text analysis using linguistic inquiry word count (LIWC), which is used to count words in psychologically meaningful categories [45,71,83,88,89]. Linguistic analysis performed by Singh et al [45] for analyzing smoking cessation behaviors showed that interrogatives in the form of seeking information were more frequently expressed in an individual's language if they belonged to the *contemplation* stage of behavior change; however, numbers were more frequently expressed in an individual's language if they belonged to the *action* stage of behavior change. Another study showed that words carrying negative affect were more frequently associated with greater substance abuse [71]. In one study, LIWC was used to measure personal pronoun use within each community to understand if the individual was tweeting about one's drinking behavior or was referencing others' behavior [83]. One study extracted psycholinguistic features from the language used on social media platforms to train a classifier to predict recovery from alcoholism [88]. Similarly, another study showed that the negative emotions or swear words, inhibition words, and love words were significantly associated with increased risk of relapse for individuals suffering from alcohol use disorder [89].

Sentiment Modeling

Out of 64 studies, 20 (31%) performed sentiment analysis to gauge the positive, negative, or neutral sentiment of individuals toward health behaviors (eg, e-cigarettes, hookah, drug abuse, vaping, and JUUL) [40,41, 43, 51,59,63, 66-68,79,80,83, 85, 86,91, 93-96,103]. Some techniques used for performing sentiment analysis included SentiWordNet 3.0 [59]; the SentiWords (sentiment words) lexicon [85]; Sentiment140 [96]; maximum entropy text classifier [79,94,95]; Mathematica 10.3 (Wolfram) [93]; SVM trained on SemEval (semantic evaluation), ISEAR (International Survey on Emotion Antecedents and Reactions) emotion data sets, and on an emotion-tagged tweet corpus [51]; and various supervised ML algorithms [40,41,43,63,66,67,80,86,91]. One study calculated sentiment scores from the Liu and Hu opinion lexicon dictionary [68], one study used National Resource Council Hashtag Sentiment Lexicons to measure the positive sentiment associated with a tweet [83], and three studies used VADER (Valence Aware Dictionary and sEntiment Reasoning), which is a lexicon and rule-based sentiment analysis tool [51,80,103].

Model Evaluation and Metrics

To evaluate the performance of the classification models, several studies divided their data sets into training and test sets, performed n-fold cross-validations, and calculated metrics such as accuracy, precision, recall, F1 score, specificity, the Matthew correlation coefficient, and area under the receiver operating characteristics (AUROC) curve. We compiled our Results

section using the F1 scores reported by various studies. If any study did not report their F1 scores, we listed the metrics they reported in their study. Most of the studies reported the F1 scores for classification tasks [40,41,43-46,48, 51, 54,55,59, 60,66-70, 72-74,80, 81,84, 87, 88,91,92, 94,95,102,103], and they ranged from 0.42 to 0.99 across various studies. Cross-validation was performed using various folds: 4-fold [59], 5-fold [67,80,82,92], 6-fold [73], and 10-fold [40, 44-46,54, 58, 60,63, 66, 68,74, 75, 81,86, 88, 91,102,103] cross-validation. Three studies reported only the accuracy values for evaluating the classifier performance [52,63,100]. One study reported only the precision of the information retrieval system [56], while two studies reported only the values obtained from AUROC curves [58,82]. One study evaluated the quality of themes identified using two approaches: supervised evaluation, by manually annotating tweets for each theme and calculating the average false-positive rate, and unsupervised evaluation, by calculating cluster purity that quantifies how coherent the theme is [78].

Quantitative Modeling Using Social Network Analysis

Out of 64 studies, 9 (13%) performed social network analysis [42,48,50,53,64,65,86,91,103]:

1. One study generated network graphs to visualize presence and co-occurrence of e-cigarette topics across different subreddits [42].
2. One study created network graphs to understand the reach of a campaign targeted to educate young individuals about harmful effects of smoking [48].
3. One study identified topics of e-cigarette-related conversations by creating a Twitter hashtag co-occurrence network [50].
4. One study analyzed structural differences in social networks of smokers and nonsmokers by analyzing the relationship of network metrics with smoking status of individuals [53].
5. One study performed affiliation network analysis by constructing two-mode network graphs to understand the association of the members of a smoking cessation community with different communication themes [64].
6. One study visualized topological and theme-based differences in social networks of members of an online smoking cessation community [65].
7. One study analyzed how an individual's social network connectivity affected their alcohol use behaviors based on the topics of discussion [86].
8. One study showed that individuals who expressed negative sentiment about drinking were more centrally located within the social network compared to other members of the community [91].
9. One study quantified the peer interactions between the members of the community using social network features (eg, in-degree, out-degree, degree, reciprocity, and clustering coefficient) [103].

The tools and software programs used for performing such analysis included the Gephi platform [48,50,65]; NetworkX, a Python package (Python Software Foundation) [86]; UCINET software (Analytic Technologies) [42,64]; and the iGraph package in R [53]. One study visualized frequent word co-occurrences by creating a sociogram using NodeXL

(Microsoft) [42]. Two studies did not specifically mention the tools they used for performing social network analysis [91,103]. Varying metrics were used for social network analysis, such as degree centrality [42,64], modularity [48,65], and in-degree and out-degree centralities [86,91]. One study used multiple metrics for analyzing social network structures, such as vertices, edges,

density, isolates, diameter, communities, betweenness centrality, closeness centrality, transitivity, clusters, and modularity [53]. Table 3 [40-46,48-55,57-89,91-103] highlights the summary of methodological functions used across various studies and also lists the specific tools used for performing those functions.

Table 3. Summary of methods and related tools used by various studies.

Methods	Tools, platforms, and programs
Linguistic analysis	Linguistic inquiry word count [45,71,83,88,89]
Sentiment analysis	SentiWordNet 3.0 [59] SentiWords (sentiment words) lexicon [85] Sentiment140 [96] Maximum entropy text classifier [79,94,95] Mathematica 10.3 [93] Various supervised machine learning algorithms [40,41,43,51,63,66,67,80,86,91] Liu and Hu opinion lexicon dictionary [68] VADER (Valence Aware Dictionary and sEntiment Reasoning) [51,80,103] National Resource Council Hashtag Sentiment Lexicon [83]
Supervised classification	Support vector machine [41,44-46,51,54,58,60,63,66-68,70,73-75,80-82,87,92,94,100,102] Logistic regression [40,41,44-46,54,58-60,72,80,89,92,94,100,102] Naïve Bayes [40,41,46,52,54,58,60,63,66,70,73-75,80,81,86,91,100] Random forest [40,41,45,54,58,70,73-75,82,84,86,91,92,100,102] Decision tree-based classifier [46,54,55,74,81,86,91] k-nearest neighbors [54,63,66,74,84] AdaBoost [46,54,86,91] Sequential minimal optimization [84] Maximum entropy text classifier [79,81,94,95] Multilayer perceptron [84] REPTree [88] Feed-forward neural network [94] Gradient boosting [48,54,94] Convolutional neural networks (CNNs) [41,70,72-75,87,100] Long short-term memory (LSTM) [41,72] LSTM-CNN [41] Bidirectional LSTM [41] Shallow neural network for text classification [100] Reinforcement neural network-gated recurrent unit [100]
Topic modeling	Quanteda software [42] Latent Dirichlet allocation [49,57,60,62,69,77,83,84,97-99,101] SAS Text Miner [61,76,85,93] Correlated topic modeling [86]
Community identification and theme or pattern recognition	k-means clustering [42] Biterm topic model [78] Agglomerative hierarchical clustering technique [102]
Social network analysis	Gephi platform [48,50,65] NetworkX (Python package) [86] UCINET software [42,64] iGraph package in R [53] NodeXL [42]

Discussion

Principal Findings

The purpose of this review was to investigate the current state of computational and quantitative techniques available for analyzing risky health behaviors, beliefs, and attitudes using online peer interactions from social media platforms. From the initial set of studies retrieved and snowballing techniques, 64 studies that met our inclusion criteria were included in this review, out of which 75% (48/64) [40-57,68-79, 82-94,97, 98, 100-102] were published in 2017 onward. This suggests that there is a growing trend in utilizing computational approaches to characterize risky health behaviors by analyzing conversational data generated from online peer interactions.

Several platforms were used as the source of data for analyzing risky health behaviors, with the most popular being open social media platforms, since 80% (51/64) of the studies utilized them as compared to intentionally designed health-related social media platforms. In terms of data collection, our results showed that Twitter was a popular source of social media data, as it provides three easy ways to access the data: Twitter Search API, Twitter Streaming API, and Twitter Firehose [104]. Some studies utilized platforms (eg, Facebook, Instagram, and Reddit) that also provide access to data through their APIs [105-107] but were not as widely used as compared to Twitter. A few studies utilized intentionally designed health-related social media platforms, such as QuitNet, Cancer Survivors Network, patient.info/forums, BecomeAnEx.org, Hello Sunday Morning blog, and the A-CHESS online discussion forum, but they did not provide any information about their data collection techniques. In terms of data types, this review included studies that primarily focused on analyzing textual data generated from online peer interactions. Thus, we excluded two studies during the full-text screening that focused on analyzing risky health behaviors through image analysis only [108,109].

Sentiments toward smoking-related products (eg, cigars, e-cigarettes, hookah, vaping, and JUUL) and identification of various themes related to the discussion of such products were widely studied using online social media platforms. Prescription drug abuse, opioid misuse, and binge drinking-related behaviors were another set of widely analyzed risky health behaviors using online social media platforms. This highlights the potential of using such platforms for the dissemination of behavioral change interventions targeting uncharted and evolving domains (eg, e-cigarettes) as well as well-charted domains (eg, alcohol use). In addition to addictive behaviors, uptake behaviors were analyzed, such as the association of physical activity patterns, sentiments, and types of behaviors (eg, running, walking, and jogging) with different geographical locations (eg, in Canada) and population demographics (eg, genders). Social media platforms were used for identifying the themes related to weight loss and obesity-related behaviors. None of the studies focused on analyzing unprotected sex-related behaviors, an important public health focus and priority, which can likely be an interesting avenue for future research. However, given the stigma, privacy concerns, and the opaque nature of the domain, access to such data sets might be limited.

The LIWC tool was widely used for linguistic feature extraction, as it is an easily accessible tool that extracts features like style words, emotional words, and parts of speech from the texts [110]. Language modeling performed using LIWC showed how the usage of language among members can be used to predict their relapse or behavior transition patterns. For topic modeling, LDA was the most commonly used tool; it analyzes latent topics based on word distribution and then assigns a distribution of topics to each document [111]. The topics discussed varied from one risky health behavior to another but mostly highlighted the attitudes and behavior patterns of individuals engaging in such behaviors. Few examples include highlighting the controversial topics related to e-cigarette and marijuana use (eg, legalization, prohibition, etc) [101], identifying topics related to the normative or cultural context surrounding e-cigarette use and alcoholic preferences [60,83], and understanding how the social environment of individuals affects their behaviors toward weight loss [98].

A wide range of supervised ML algorithms were used for the content and sentiment analysis of the data generated from online peer interactions. Most of the studies utilized traditional ML models (eg, SVM, LR, RF, DT, and KNN) for text classification purposes. Only a few studies [41,70,72-75,87,100] utilized deep learning models (eg, CNNs and LSTMs) for text as well as image and video classification tasks. In terms of performance evaluation, the following results were observed:

1. In 4 out of 64 (6%) studies [41,72-74], the performance of deep learning models on classification tasks was better compared to the traditional ML classifiers (eg, the deep learning model had an AUROC curve of 0.65 as compared to the baseline LR model, which had an AUROC curve of 0.54 [72]).
2. In 1 study out of 64 (2%) [75], the deep learning model marginally outperformed the traditional ML classifier: RF (accuracy 70.1%) and deep CNN (accuracy 70.4%).
3. In another 2 studies out of 64 (3%) [70,100], the performance of deep learning models on classification tasks was lower compared to the traditional ML classifiers (eg, RF [accuracy 93.4%] performed better than CNN [accuracy 60.1%] [100]).

The majority of the studies included in this review focused only on textual data analysis of online peer interactions, while only one study performed additional analysis using image data [72], and only one performed textual, image, and video data analysis [87]. Few studies [41,55,56,64,65,70,72-75] created word vectors using pretrained word embeddings (eg, GloVe, word2vec, drug chatter word embeddings, LSA, RI, and SGNS). These were trained using different types of corpora (eg, the Wikipedia corpus [56,72], the TASA corpus [55,64,65], or a domain-specific corpus [41,70,72,74,75]). The performance of classifiers using pretrained word embeddings ranged from 0.99 to 0.55 in terms of F1 scores.

Some of the studies included in this review also performed network analysis [42,48,50,53,64,65,86,91,103]. The Gephi platform [112] and UCINET software [113] were widely used tools for analyzing online social ties. One study characterized the role of content-specific social influence patterns underlying

peer-to-peer communication using affiliation exposure models and the two-mode version of the network autocorrelation model [64]. One study analyzed the social network structure of smokers and compared it with the network structure of nonsmokers to understand the factors related to the social influence that might affect addictive tobacco-related behaviors [53]. Such network analysis can help us understand the context of communication, which can eventually guide the development of tangible technology features by health researchers and technology developers [114,115].

One study [85] analyzed online peer interactions based on a communication model called the dynamic transactional model [116], which is suitable for modeling two-way communication between individuals. Very few studies [42,45,55,64,65,97] linked theoretical constructs that define behavior change in analyzing content generated from social media platforms, such as social cognitive theory [117], the transtheoretical model of change [118], the health belief model [119], and the taxonomy of behavior change techniques [120]. The online peer interactions should be analyzed using theoretical frameworks that can lead to the development of empirically grounded digital health interventions for promoting health and positive behavior changes [121,122]. Theory-driven large-scale analysis of social media data sets will yield insights into the specific processes of behavior change that manifest in peer interactions. The analysis of these data sets in conjunction with theoretical constructs can aid in enhancing our knowledge of how social influence plays a major role in diffusing health information and modifying individual health behaviors. This can have implications for the development of high-yield interventions for individuals and populations based on their risky health behavior, thereby enabling individuals to make positive lifestyle changes and improving their quality of life.

It is also important to understand that online social media platforms can be used for disseminating health-related misinformation as well [123]. The COVID-19 pandemic has provided us with abundant evidence that highlights the urgency to address public concerns related to misinformation that is plaguing social media, which can negatively impact health-related behaviors of individuals [124,125]. Also, the ground truth of aggregated trends extracted from information disseminated through these platforms is reflective of community perceptions only to a certain extent because of the large amount of content push by automated bots [126]. Studies have shown how misinformation also impacts risky health behaviors (eg, misleading marketing claims about e-cigarettes [127] and alcohol use [128]). Future work should focus on leveraging the techniques described in this review for analysis of misinformation diffused throughout online social media platforms to enhance the utility and positive impact of these platforms.

Limitations

Our review is not without limitations. Firstly, we included studies related to risky health behaviors alone; however, studies focusing on other public health domains (eg, epidemiology [129] and surveillance [130]) or studies focusing on chronic health conditions (eg, diabetes [131,132] and cancer [133]), as

well as clinical and health outcomes [134,135], can provide us with a comprehensive understanding of how data generated from social media platforms are analyzed for various public health applications by leveraging computational modeling and high-throughput analytics. The domain of infodemiology and infoveillance is quite broad and includes various other aspects of risky health behaviors that were not included in this review (eg, mining consumer opinions toward online marketing of e-cigarettes [136,137], or understanding their reactions toward media coverage [138,139] or policy regulations [140,141] concerning such products). Secondly, we only focused on studies that primarily performed textual data analysis. Even though we did include studies that reported image or video data analysis along with textual data analysis [72,87], we did not include studies that solely described image or video data analysis [108,109]. These studies can provide useful insights into ML trade-offs and computational scalability as related to varying data density, heterogeneity, and inferential granularity.

Finally, given the constraints of our search strategy, we might have missed some studies from the infodemiology and infoveillance domain; for example, an initial exploration of the literature search in this domain [142] had resulted in a total of 397 studies, out of which 23 studies were relevant for inclusion in this review. Of these, 15 studies were captured by our search strategy and included in the review [40,41,43,50,51,54,61-63,66,68-70,80,95], and an additional one was included as part of the snowballing efforts [47]. However, the remaining seven were not identified by our search strategy [143-149]. Broad methodological descriptions or excessively granular terminology use capturing ML methods in metadata, titles, abstracts, and keywords are noted in these studies. For consistency and to limit bias with studies in other journals, we have not included these studies in the review. Future researchers conducting similar reviews should ensure the inclusion of terms that capture the interdisciplinary nature of studies (eg, infodemiology), analytical functions (eg, text classification, content analysis, and topic modeling), and analytical techniques (eg, LDA) for the exhaustive representation of related works that leverage SMAaRT for risky behavior modeling and analysis.

Conclusions

Our review shows that online discourse related to risky health behaviors on social media platforms can span multiple topics that include nicotine dependence, alcohol use, drug or substance abuse, physical activity patterns, and obesity-related behaviors. This results in the generation of large amounts of digitally archived data, which can provide a deeper understanding of the organic manifestation and natural evolution of health-related behavior change processes.

Our review highlights the characteristics of social media platforms (eg, general-purpose vs health-focused platforms and ease of data access for secondary analysis), the robustness of methods used for analyzing peer interactions within these platforms, and an overview of a wide variety of text mining and network modeling tools available to conduct analyses of social media data sets at scale. Our review allows us to consolidate the methodological underpinnings and enhance our

understanding of how social media can be leveraged for nuanced behavioral modeling and representation. This can ultimately inform and lead to the formulation of persuasive health communication and effective behavior modification technologies targeting inter- and intrapersonal psychosocial processes

distributed at the individual and population levels. It is also important to understand the merits and shortfalls of existing computational studies to assess the generalizability and strength of the downstream predictive models and data-driven interventions resulting from such large-scale analyses.

Acknowledgments

Research reported in this publication was supported by the National Library of Medicine and National Cancer Institute of the National Institutes of Health (award numbers 1R01LM012974-01A1 and 3R01LM012974-02S1). The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

Conflicts of Interest

None declared.

Multimedia Appendix 1

A detailed summary of the studies included in the review.

[[PDF File \(Adobe PDF File\), 468 KB - publichealth_v6i4e21660_app1.pdf](#)]

References

1. National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP). About chronic diseases. Centers for Disease Control and Prevention. URL: <https://www.cdc.gov/chronicdisease/about/index.htm> [accessed 2020-06-04]
2. National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP). Health and economic costs of chronic diseases. Centers for Disease Control and Prevention. URL: <https://www.cdc.gov/chronicdisease/about/costs/index.htm> [accessed 2020-06-05]
3. Barlow J, Wright C, Sheasby J, Turner A, Hainsworth J. Self-management approaches for people with chronic conditions: A review. *Patient Educ Couns* 2002;48(2):177-187. [doi: [10.1016/s0738-3991\(02\)00032-0](https://doi.org/10.1016/s0738-3991(02)00032-0)] [Medline: [12401421](https://pubmed.ncbi.nlm.nih.gov/12401421/)]
4. Gallant MP. The influence of social support on chronic illness self-management: A review and directions for research. *Health Educ Behav* 2003 Apr;30(2):170-195. [doi: [10.1177/1090198102251030](https://doi.org/10.1177/1090198102251030)] [Medline: [12693522](https://pubmed.ncbi.nlm.nih.gov/12693522/)]
5. Mokdad A, Remington P. Measuring health behaviors in populations. *Prev Chronic Dis* 2010 Jul;7(4):A75 [FREE Full text] [Medline: [20550833](https://pubmed.ncbi.nlm.nih.gov/20550833/)]
6. Ekong G, Kavookjian J. Motivational interviewing and outcomes in adults with type 2 diabetes: A systematic review. *Patient Educ Couns* 2016 Jun;99(6):944-952. [doi: [10.1016/j.pec.2015.11.022](https://doi.org/10.1016/j.pec.2015.11.022)] [Medline: [26699083](https://pubmed.ncbi.nlm.nih.gov/26699083/)]
7. Hicks JL, Althoff T, Sosic R, Kuhar P, Bostjancic B, King AC, et al. Best practices for analyzing large-scale health data from wearables and smartphone apps. *NPJ Digit Med* 2019;2:45 [FREE Full text] [doi: [10.1038/s41746-019-0121-1](https://doi.org/10.1038/s41746-019-0121-1)] [Medline: [31304391](https://pubmed.ncbi.nlm.nih.gov/31304391/)]
8. Shiffman S, Stone AA, Hufford MR. Ecological momentary assessment. *Annu Rev Clin Psychol* 2008;4:1-32. [doi: [10.1146/annurev.clinpsy.3.022806.091415](https://doi.org/10.1146/annurev.clinpsy.3.022806.091415)] [Medline: [18509902](https://pubmed.ncbi.nlm.nih.gov/18509902/)]
9. Laranjo L, Arguel A, Neves AL, Gallagher AM, Kaplan R, Mortimer N, et al. The influence of social networking sites on health behavior change: A systematic review and meta-analysis. *J Am Med Inform Assoc* 2015 Jan;22(1):243-256 [FREE Full text] [doi: [10.1136/amiajnl-2014-002841](https://doi.org/10.1136/amiajnl-2014-002841)] [Medline: [25005606](https://pubmed.ncbi.nlm.nih.gov/25005606/)]
10. Eysenbach G. Infodemiology and infoveillance: Framework for an emerging set of public health informatics methods to analyze search, communication and publication behavior on the Internet. *J Med Internet Res* 2009 Mar 27;11(1):e11 [FREE Full text] [doi: [10.2196/jmir.1157](https://doi.org/10.2196/jmir.1157)] [Medline: [19329408](https://pubmed.ncbi.nlm.nih.gov/19329408/)]
11. Eysenbach G. Infodemiology: Tracking flu-related searches on the web for syndromic surveillance. *AMIA Annu Symp Proc* 2006:244-248 [FREE Full text] [Medline: [17238340](https://pubmed.ncbi.nlm.nih.gov/17238340/)]
12. Ginsberg J, Mohebbi MH, Patel RS, Brammer L, Smolinski MS, Brilliant L. Detecting influenza epidemics using search engine query data. *Nature* 2009 Feb 19;457(7232):1012-1014. [doi: [10.1038/nature07634](https://doi.org/10.1038/nature07634)] [Medline: [19020500](https://pubmed.ncbi.nlm.nih.gov/19020500/)]
13. Schomberg JP, Haimson OL, Hayes GR, Anton-Culver H. Supplementing public health inspection via social media. *PLoS One* 2016;11(3):e0152117 [FREE Full text] [doi: [10.1371/journal.pone.0152117](https://doi.org/10.1371/journal.pone.0152117)] [Medline: [27023681](https://pubmed.ncbi.nlm.nih.gov/27023681/)]
14. Yeung D. Social media as a catalyst for policy action and social change for health and well-being: Viewpoint. *J Med Internet Res* 2018 Mar 19;20(3):e94 [FREE Full text] [doi: [10.2196/jmir.8508](https://doi.org/10.2196/jmir.8508)] [Medline: [29555624](https://pubmed.ncbi.nlm.nih.gov/29555624/)]
15. Zimmerman RK, Wolfe RM, Fox DE, Fox JR, Nowalk MP, Troy JA, et al. Vaccine criticism on the World Wide Web. *J Med Internet Res* 2005 Jun 29;7(2):e17. [doi: [10.2196/jmir.7.2.e17](https://doi.org/10.2196/jmir.7.2.e17)] [Medline: [15998608](https://pubmed.ncbi.nlm.nih.gov/15998608/)]
16. Li A, Jiao D, Liu X, Zhu T. A comparison of the psycholinguistic styles of schizophrenia-related stigma and depression-related stigma on social media: Content analysis. *J Med Internet Res* 2020 Apr 21;22(4):e16470 [FREE Full text] [doi: [10.2196/16470](https://doi.org/10.2196/16470)] [Medline: [32314969](https://pubmed.ncbi.nlm.nih.gov/32314969/)]

17. Vargas Meza X, Yamanaka T. Food communication and its related sentiment in local and organic food videos on YouTube. *J Med Internet Res* 2020 Aug 10;22(8):e16761 [FREE Full text] [doi: [10.2196/16761](https://doi.org/10.2196/16761)] [Medline: [32773370](https://pubmed.ncbi.nlm.nih.gov/32773370/)]
18. Pawar AS, Nagpal S, Pawar N, Lerman LO, Eirin A. General public's information-seeking patterns of topics related to obesity: Google Trends analysis. *JMIR Public Health Surveill* 2020 Aug 11;6(3):e20923 [FREE Full text] [doi: [10.2196/20923](https://doi.org/10.2196/20923)] [Medline: [32633725](https://pubmed.ncbi.nlm.nih.gov/32633725/)]
19. Abd-Alrazaq A, Alhuwail D, Househ M, Hamdi M, Shah Z. Top concerns of tweeters curing the COVID-19 pandemic: Infoveillance study. *J Med Internet Res* 2020 Apr 21;22(4):e19016 [FREE Full text] [doi: [10.2196/19016](https://doi.org/10.2196/19016)] [Medline: [32287039](https://pubmed.ncbi.nlm.nih.gov/32287039/)]
20. Wahbeh A, Nasrallah T, Al-Ramahi M, El-Gayar O. Mining physicians' opinions on social media to obtain insights into COVID-19: Mixed methods analysis. *JMIR Public Health Surveill* 2020 Jun 18;6(2):e19276 [FREE Full text] [doi: [10.2196/19276](https://doi.org/10.2196/19276)] [Medline: [32421686](https://pubmed.ncbi.nlm.nih.gov/32421686/)]
21. Kietzmann JH, Hermkens K, McCarthy IP, Silvestre BS. Social media? Get serious! Understanding the functional building blocks of social media. *Bus Horiz* 2011 May;54(3):241-251. [doi: [10.1016/j.bushor.2011.01.005](https://doi.org/10.1016/j.bushor.2011.01.005)]
22. Digital in 2019. We Are Social. New York, NY: We Are Social URL: <https://wearesocial.com/global-digital-report-2019> [accessed 2020-06-03]
23. Chou WS, Hunt YM, Beckjord EB, Moser RP, Hesse BW. Social media use in the United States: Implications for health communication. *J Med Internet Res* 2009 Nov 27;11(4):e48 [FREE Full text] [doi: [10.2196/jmir.1249](https://doi.org/10.2196/jmir.1249)] [Medline: [19945947](https://pubmed.ncbi.nlm.nih.gov/19945947/)]
24. Fisher J, Clayton M. Who gives a tweet: Assessing patients' interest in the use of social media for health care. *Worldviews Evid Based Nurs* 2012 Apr;9(2):100-108. [doi: [10.1111/j.1741-6787.2012.00243.x](https://doi.org/10.1111/j.1741-6787.2012.00243.x)] [Medline: [22432730](https://pubmed.ncbi.nlm.nih.gov/22432730/)]
25. Looyestyn J, Kernot J, Boshoff K, Maher C. A web-based, social networking beginners' running intervention for adults aged 18 to 50 years delivered via a Facebook group: Randomized controlled trial. *J Med Internet Res* 2018 Feb 26;20(2):e67 [FREE Full text] [doi: [10.2196/jmir.7862](https://doi.org/10.2196/jmir.7862)] [Medline: [29483065](https://pubmed.ncbi.nlm.nih.gov/29483065/)]
26. Cheung YTD, Chan CHH, Lai CJ, Chan WFV, Wang MP, Li HCW, et al. Using WhatsApp and Facebook online social groups for smoking relapse prevention for recent quitters: A pilot pragmatic cluster randomized controlled trial. *J Med Internet Res* 2015 Oct 22;17(10):e238 [FREE Full text] [doi: [10.2196/jmir.4829](https://doi.org/10.2196/jmir.4829)] [Medline: [26494159](https://pubmed.ncbi.nlm.nih.gov/26494159/)]
27. van Woudenberg TJ, Bevelander KE, Burk WJ, Smit CR, Buijs L, Buijzen M. A randomized controlled trial testing a social network intervention to promote physical activity among adolescents. *BMC Public Health* 2018 Apr 23;18(1):542 [FREE Full text] [doi: [10.1186/s12889-018-5451-4](https://doi.org/10.1186/s12889-018-5451-4)] [Medline: [29685112](https://pubmed.ncbi.nlm.nih.gov/29685112/)]
28. Umberson D, Crosnoe R, Reczek C. Social relationships and health behavior across life course. *Annu Rev Sociol* 2010 Aug 01;36:139-157. [doi: [10.1146/annurev-soc-070308-120011](https://doi.org/10.1146/annurev-soc-070308-120011)] [Medline: [21921974](https://pubmed.ncbi.nlm.nih.gov/21921974/)]
29. Christakis NA, Fowler JH. The collective dynamics of smoking in a large social network. *N Engl J Med* 2008 May 22;358(21):2249-2258 [FREE Full text] [doi: [10.1056/NEJMs0706154](https://doi.org/10.1056/NEJMs0706154)] [Medline: [18499567](https://pubmed.ncbi.nlm.nih.gov/18499567/)]
30. Korda H, Itani Z. Harnessing social media for health promotion and behavior change. *Health Promot Pract* 2013 Jan;14(1):15-23. [doi: [10.1177/1524839911405850](https://doi.org/10.1177/1524839911405850)] [Medline: [21558472](https://pubmed.ncbi.nlm.nih.gov/21558472/)]
31. Cobb NK, Graham AL, Bock BC, Papandonatos G, Abrams DB. Initial evaluation of a real-world internet smoking cessation system. *Nicotine Tob Res* 2005 Apr;7(2):207-216 [FREE Full text] [doi: [10.1080/14622200500055319](https://doi.org/10.1080/14622200500055319)] [Medline: [16036277](https://pubmed.ncbi.nlm.nih.gov/16036277/)]
32. Wherever you are in your quit, we're here for you!. BecomeAnEX Community. URL: <https://excommunity.becomeanex.org/> [accessed 2020-06-13]
33. Centola D. Social media and the science of health behavior. *Circulation* 2013 May 28;127(21):2135-2144. [doi: [10.1161/CIRCULATIONAHA.112.101816](https://doi.org/10.1161/CIRCULATIONAHA.112.101816)] [Medline: [23716382](https://pubmed.ncbi.nlm.nih.gov/23716382/)]
34. Ayers JW, Althouse BM, Dredze M. Could behavioral medicine lead the web data revolution? *JAMA* 2014 Apr 09;311(14):1399-1400 [FREE Full text] [doi: [10.1001/jama.2014.1505](https://doi.org/10.1001/jama.2014.1505)] [Medline: [24577162](https://pubmed.ncbi.nlm.nih.gov/24577162/)]
35. Chuang K, Yang C. A study of informational support exchanges in MedHelp alcoholism community. In: Proceedings of the 5th International Conference on Social Computing, Behavioral-Cultural Modeling, and Prediction. Berlin, Germany: Springer; 2012 Presented at: 5th International Conference on Social Computing, Behavioral-Cultural Modeling, and Prediction; April 3-5, 2012; College Park, MD p. 9-17. [doi: [10.1007/978-3-642-29047-3_2](https://doi.org/10.1007/978-3-642-29047-3_2)]
36. Hwang KO, Ottenbacher AJ, Green AP, Cannon-Diehl MR, Richardson O, Bernstam EV, et al. Social support in an internet weight loss community. *Int J Med Inform* 2010 Jan;79(1):5-13 [FREE Full text] [doi: [10.1016/j.ijmedinf.2009.10.003](https://doi.org/10.1016/j.ijmedinf.2009.10.003)] [Medline: [19945338](https://pubmed.ncbi.nlm.nih.gov/19945338/)]
37. Myneni S, Cobb N, Cohen T. In pursuit of theoretical ground in behavior change support systems: Analysis of peer-to-peer communication in a health-related online community. *J Med Internet Res* 2016 Feb 02;18(2):e28 [FREE Full text] [doi: [10.2196/jmir.4671](https://doi.org/10.2196/jmir.4671)] [Medline: [26839162](https://pubmed.ncbi.nlm.nih.gov/26839162/)]
38. Yu K, Beam AL, Kohane IS. Artificial intelligence in healthcare. *Nat Biomed Eng* 2018 Oct;2(10):719-731. [doi: [10.1038/s41551-018-0305-z](https://doi.org/10.1038/s41551-018-0305-z)] [Medline: [31015651](https://pubmed.ncbi.nlm.nih.gov/31015651/)]
39. Liberati A, Altman DG, Tetzlaff J, Mulrow C, Gøtzsche PC, Ioannidis JPA, et al. The PRISMA statement for reporting systematic reviews and meta-analyses of studies that evaluate health care interventions: Explanation and elaboration. *PLoS Med* 2009 Jul 21;6(7):e1000100 [FREE Full text] [doi: [10.1371/journal.pmed.1000100](https://doi.org/10.1371/journal.pmed.1000100)] [Medline: [19621070](https://pubmed.ncbi.nlm.nih.gov/19621070/)]

40. Benson R, Hu M, Chen AT, Nag S, Zhu S, Conway M. Investigating the attitudes of adolescents and young adults towards JUUL: Computational study using Twitter data. *JMIR Public Health Surveill* 2020 Sep 02;6(3):e19975 [FREE Full text] [doi: [10.2196/19975](https://doi.org/10.2196/19975)] [Medline: [32876579](https://pubmed.ncbi.nlm.nih.gov/32876579/)]
41. Visweswaran S, Colditz JB, O'Halloran P, Han N, Taneja SB, Welling J, et al. Machine learning classifiers for Twitter surveillance of vaping: Comparative machine learning study. *J Med Internet Res* 2020 Aug 12;22(8):e17478 [FREE Full text] [doi: [10.2196/17478](https://doi.org/10.2196/17478)] [Medline: [32784184](https://pubmed.ncbi.nlm.nih.gov/32784184/)]
42. Barker JO, Rohde JA. Topic clustering of e-cigarette submissions among Reddit communities: A network perspective. *Health Educ Behav* 2019 Dec;46(2_suppl):59-68. [doi: [10.1177/1090198119863770](https://doi.org/10.1177/1090198119863770)] [Medline: [31742448](https://pubmed.ncbi.nlm.nih.gov/31742448/)]
43. Chu K, Colditz J, Malik M, Yates T, Primack B. Identifying key target audiences for public health campaigns: Leveraging machine learning in the case of hookah tobacco smoking. *J Med Internet Res* 2019 Jul 08;21(7):e12443 [FREE Full text] [doi: [10.2196/12443](https://doi.org/10.2196/12443)] [Medline: [31287063](https://pubmed.ncbi.nlm.nih.gov/31287063/)]
44. Czaplicki L, Kostygina G, Kim Y, Perks SN, Szczypka G, Emery SL, et al. Characterising JUUL-related posts on Instagram. *Tob Control* 2020 Nov;29(6):612-617. [doi: [10.1136/tobaccocontrol-2018-054824](https://doi.org/10.1136/tobaccocontrol-2018-054824)] [Medline: [31266903](https://pubmed.ncbi.nlm.nih.gov/31266903/)]
45. Singh T, Perez C, Roberts K, Cobb N, Franklin A, Myneni S. Characterization of behavioral transitions through social media analysis: A mixed-methods approach. *Stud Health Technol Inform* 2019 Aug 21;264:1228-1232. [doi: [10.3233/SHTI190422](https://doi.org/10.3233/SHTI190422)] [Medline: [31438121](https://pubmed.ncbi.nlm.nih.gov/31438121/)]
46. Wang X, Zhao K, Cha S, Amato MS, Cohn AM, Pearson JL, et al. Mining user-generated content in an online smoking cessation community to identify smoking status: A machine learning approach. *Decis Support Syst* 2019 Jan;116:26-34. [doi: [10.1016/j.dss.2018.10.005](https://doi.org/10.1016/j.dss.2018.10.005)] [Medline: [31885411](https://pubmed.ncbi.nlm.nih.gov/31885411/)]
47. Allem J, Dharmapuri L, Leventhal A, Unger J, Boley Cruz T. Hookah-related posts to Twitter from 2017 to 2018: Thematic analysis. *J Med Internet Res* 2018 Nov 19;20(11):e11669 [FREE Full text] [doi: [10.2196/11669](https://doi.org/10.2196/11669)] [Medline: [30455162](https://pubmed.ncbi.nlm.nih.gov/30455162/)]
48. Chew R, Kim A, Chen V, Ruddell P, Morgan-Lopez A. Assessing target audiences of digital public health campaigns: A computational approach. In: *Proceedings of the 11th International Conference on Social Computing, Behavioral-Cultural Modeling and Prediction and Behavior Representation in Modeling and Simulation*. Cham, Switzerland: Springer; 2018 Presented at: 11th International Conference on Social Computing, Behavioral-Cultural Modeling and Prediction and Behavior Representation in Modeling and Simulation; July 10-13, 2018; Washington, DC p. 286-291. [doi: [10.1007/978-3-319-93372-6_32](https://doi.org/10.1007/978-3-319-93372-6_32)]
49. Zhou J, Zhang Q, Zeng DD, Tsui KL. Influence of flavors on the propagation of e-cigarette-related information: Social media study. *JMIR Public Health Surveill* 2018 Mar 23;4(1):e27 [FREE Full text] [doi: [10.2196/publichealth.7998](https://doi.org/10.2196/publichealth.7998)] [Medline: [29572202](https://pubmed.ncbi.nlm.nih.gov/29572202/)]
50. Allem J, Ferrara E, Uppu SP, Cruz TB, Unger JB. E-cigarette surveillance with social media data: Social bots, emerging topics, and trends. *JMIR Public Health Surveill* 2017 Dec 20;3(4):e98 [FREE Full text] [doi: [10.2196/publichealth.8641](https://doi.org/10.2196/publichealth.8641)] [Medline: [29263018](https://pubmed.ncbi.nlm.nih.gov/29263018/)]
51. Allem J, Ramanujam J, Lerman K, Chu K, Boley Cruz T, Unger JB. Identifying sentiment of hookah-related posts on Twitter. *JMIR Public Health Surveill* 2017 Oct 18;3(4):e74 [FREE Full text] [doi: [10.2196/publichealth.8133](https://doi.org/10.2196/publichealth.8133)] [Medline: [29046267](https://pubmed.ncbi.nlm.nih.gov/29046267/)]
52. Dai H, Hao J. Mining social media data for opinion polarities about electronic cigarettes. *Tob Control* 2017 Mar;26(2):175-180. [doi: [10.1136/tobaccocontrol-2015-052818](https://doi.org/10.1136/tobaccocontrol-2015-052818)] [Medline: [26980151](https://pubmed.ncbi.nlm.nih.gov/26980151/)]
53. Fu L, Jacobs MA, Brookover J, Valente TW, Cobb NK, Graham AL. An exploration of the Facebook social networks of smokers and non-smokers. *PLoS One* 2017;12(11):e0187332 [FREE Full text] [doi: [10.1371/journal.pone.0187332](https://doi.org/10.1371/journal.pone.0187332)] [Medline: [29095958](https://pubmed.ncbi.nlm.nih.gov/29095958/)]
54. Kim A, Miano T, Chew R, Eggers M, Nonnemaker J. Classification of Twitter users who tweet about e-cigarettes. *JMIR Public Health Surveill* 2017 Sep 26;3(3):e63 [FREE Full text] [doi: [10.2196/publichealth.8060](https://doi.org/10.2196/publichealth.8060)] [Medline: [28951381](https://pubmed.ncbi.nlm.nih.gov/28951381/)]
55. Sridharan V, Cohen T, Cobb N, Myneni S. Characterization of Temporal Semantic Shifts of Peer-to-Peer Communication in a Health-Related Online Community: Implications for Data-driven Health Promotion. *AMIA Annu Symp Proc* 2017;2016:1977-1986 Published 2017 Feb 10 [FREE Full text] [Medline: [28269957](https://pubmed.ncbi.nlm.nih.gov/28269957/)]
56. Sridharan V, Cohen T, Cobb N, Myneni S. Temporal trends of psychosociobehavioral factors underlying tobacco use: A semi-automated exploratory analysis of peer-to-peer communication in a health-related online community. *Stud Health Technol Inform* 2017;237:123-129 [FREE Full text] [Medline: [28479554](https://pubmed.ncbi.nlm.nih.gov/28479554/)]
57. Westmaas JL, McDonald BR, Portier KM. Topic modeling of smoking- and cessation-related posts to the American Cancer Society's Cancer Survivor Network (CSN): Implications for cessation treatment for cancer survivors who smoke. *Nicotine Tob Res* 2017 Aug 01;19(8):952-959. [doi: [10.1093/ntr/ntx064](https://doi.org/10.1093/ntr/ntx064)] [Medline: [28340059](https://pubmed.ncbi.nlm.nih.gov/28340059/)]
58. Aphinyanaphongs Y, Lulejian A, Brown D, Bonneau R, Krebs P. Text classification for automatic detection of e-cigarette use and use for smoking cessation from Twitter: A feasibility pilot. *Pac Symp Biocomput* 2016;21:480-491 [FREE Full text] [doi: [10.1142/9789814749411_0044](https://doi.org/10.1142/9789814749411_0044)] [Medline: [26776211](https://pubmed.ncbi.nlm.nih.gov/26776211/)]
59. Kavuluru R, Sabbir AKM. Toward automated e-cigarette surveillance: Spotting e-cigarette proponents on Twitter. *J Biomed Inform* 2016 Jun;61:19-26 [FREE Full text] [doi: [10.1016/j.jbi.2016.03.006](https://doi.org/10.1016/j.jbi.2016.03.006)] [Medline: [26975599](https://pubmed.ncbi.nlm.nih.gov/26975599/)]

60. Kostygina G, Tran H, Shi Y, Kim Y, Emery S. 'Sweeter than a swisher': Amount and themes of little cigar and cigarillo content on Twitter. *Tob Control* 2016 Oct;25(Suppl 1):i75-i82 [FREE Full text] [doi: [10.1136/tobaccocontrol-2016-053094](https://doi.org/10.1136/tobaccocontrol-2016-053094)] [Medline: [27697951](https://pubmed.ncbi.nlm.nih.gov/27697951/)]
61. Lazard AJ, Saffer AJ, Wilcox GB, Chung AD, Mackert MS, Bernhardt JM. E-cigarette social media messages: A text mining analysis of marketing and consumer conversations on Twitter. *JMIR Public Health Surveill* 2016 Dec 12;2(2):e171 [FREE Full text] [doi: [10.2196/publichealth.6551](https://doi.org/10.2196/publichealth.6551)] [Medline: [27956376](https://pubmed.ncbi.nlm.nih.gov/27956376/)]
62. Chen AT, Zhu S, Conway M. What online communities can tell us about electronic cigarettes and hookah use: A study using text mining and visualization techniques. *J Med Internet Res* 2015 Sep 29;17(9):e220 [FREE Full text] [doi: [10.2196/jmir.4517](https://doi.org/10.2196/jmir.4517)] [Medline: [26420469](https://pubmed.ncbi.nlm.nih.gov/26420469/)]
63. Cole-Lewis H, Varghese A, Sanders A, Schwarz M, Pugatch J, Augustson E. Assessing electronic cigarette-related tweets for sentiment and content using supervised machine learning. *J Med Internet Res* 2015 Aug 25;17(8):e208 [FREE Full text] [doi: [10.2196/jmir.4392](https://doi.org/10.2196/jmir.4392)] [Medline: [26307512](https://pubmed.ncbi.nlm.nih.gov/26307512/)]
64. Myneni S, Fujimoto K, Cobb N, Cohen T. Content-driven analysis of an online community for smoking cessation: Integration of qualitative techniques, automated text analysis, and affiliation networks. *Am J Public Health* 2015 Jun;105(6):1206-1212. [doi: [10.2105/AJPH.2014.302464](https://doi.org/10.2105/AJPH.2014.302464)] [Medline: [25880942](https://pubmed.ncbi.nlm.nih.gov/25880942/)]
65. Myneni S, Cobb NK, Cohen T. Finding meaning in social media: Content-based social network analysis of QuitNet to identify new opportunities for health promotion. *Stud Health Technol Inform* 2013;192:807-811. [Medline: [23920669](https://pubmed.ncbi.nlm.nih.gov/23920669/)]
66. Myslín M, Zhu S, Chapman W, Conway M. Using Twitter to examine smoking behavior and perceptions of emerging tobacco products. *J Med Internet Res* 2013 Aug 29;15(8):e174 [FREE Full text] [doi: [10.2196/jmir.2534](https://doi.org/10.2196/jmir.2534)] [Medline: [23989137](https://pubmed.ncbi.nlm.nih.gov/23989137/)]
67. Sofean M, Smith M. Sentiment analysis on smoking in social networks. *Stud Health Technol Inform* 2013;192:1118. [Medline: [23920892](https://pubmed.ncbi.nlm.nih.gov/23920892/)]
68. Kim MG, Kim J, Kim SC, Jeong J. Twitter analysis of the nonmedical use and side effects of methylphenidate: Machine learning study. *J Med Internet Res* 2020 Feb 24;22(2):e16466 [FREE Full text] [doi: [10.2196/16466](https://doi.org/10.2196/16466)] [Medline: [32130160](https://pubmed.ncbi.nlm.nih.gov/32130160/)]
69. Nasralah T, El-Gayar O, Wang Y. Social media text mining framework for drug abuse: Development and validation study with an opioid crisis case analysis. *J Med Internet Res* 2020 Aug 13;22(8):e18350 [FREE Full text] [doi: [10.2196/18350](https://doi.org/10.2196/18350)] [Medline: [32788147](https://pubmed.ncbi.nlm.nih.gov/32788147/)]
70. O'Connor K, Sarker A, Perrone J, Gonzalez Hernandez G. Promoting reproducible research for characterizing nonmedical use of medications through data annotation: Description of a Twitter corpus and guidelines. *J Med Internet Res* 2020 Feb 26;22(2):e15861 [FREE Full text] [doi: [10.2196/15861](https://doi.org/10.2196/15861)] [Medline: [32130117](https://pubmed.ncbi.nlm.nih.gov/32130117/)]
71. Desrosiers A, Vine V, Kershaw T. "R U Mad?": Computerized text analysis of affect in social media relates to stress and substance use among ethnic minority emerging adult males. *Anxiety Stress Coping* 2019 Jan;32(1):109-123. [doi: [10.1080/10615806.2018.1539964](https://doi.org/10.1080/10615806.2018.1539964)] [Medline: [30373396](https://pubmed.ncbi.nlm.nih.gov/30373396/)]
72. Hassanpour S, Tomita N, DeLise T, Crosier B, Marsch LA. Identifying substance use risk based on deep neural networks and Instagram social media data. *Neuropsychopharmacology* 2019 Feb;44(3):487-494 [FREE Full text] [doi: [10.1038/s41386-018-0247-x](https://doi.org/10.1038/s41386-018-0247-x)] [Medline: [30356094](https://pubmed.ncbi.nlm.nih.gov/30356094/)]
73. Hu H, Phan N, Geller J, Iezzi S, Vo H, Dou D, et al. An ensemble deep learning model for drug abuse detection in sparse Twitter-sphere. *Stud Health Technol Inform* 2019 Aug 21;264:163-167. [doi: [10.3233/SHTI190204](https://doi.org/10.3233/SHTI190204)] [Medline: [31437906](https://pubmed.ncbi.nlm.nih.gov/31437906/)]
74. Sarker A, Gonzalez-Hernandez G, Ruan Y, Perrone J. Machine learning and natural language processing for geolocation-centric monitoring and characterization of opioid-related social media chatter. *JAMA Netw Open* 2019 Nov 01;2(11):e1914672 [FREE Full text] [doi: [10.1001/jamanetworkopen.2019.14672](https://doi.org/10.1001/jamanetworkopen.2019.14672)] [Medline: [31693125](https://pubmed.ncbi.nlm.nih.gov/31693125/)]
75. Sarker A, Gonzalez-Hernandez G, Perrone J. Towards automating location-specific opioid toxicosurveillance from Twitter via data science methods. *Stud Health Technol Inform* 2019 Aug 21;264:333-337 [FREE Full text] [doi: [10.3233/SHTI190238](https://doi.org/10.3233/SHTI190238)] [Medline: [31437940](https://pubmed.ncbi.nlm.nih.gov/31437940/)]
76. Glowacki EM, Glowacki JB, Wilcox GB. A text-mining analysis of the public's reactions to the opioid crisis. *Subst Abuse* 2018;39(2):129-133. [doi: [10.1080/08897077.2017.1356795](https://doi.org/10.1080/08897077.2017.1356795)] [Medline: [28723265](https://pubmed.ncbi.nlm.nih.gov/28723265/)]
77. Graves RL, Tufts C, Meisel ZF, Polsky D, Ungar L, Merchant RM. Opioid discussion in the Twittersphere. *Subst Use Misuse* 2018 Nov 10;53(13):2132-2139 [FREE Full text] [doi: [10.1080/10826084.2018.1458319](https://doi.org/10.1080/10826084.2018.1458319)] [Medline: [29659320](https://pubmed.ncbi.nlm.nih.gov/29659320/)]
78. Kalyanam J, Katsuki T, Lanckriet GRG, Mackey TK. Exploring trends of nonmedical use of prescription drugs and polydrug abuse in the Twittersphere using unsupervised machine learning. *Addict Behav* 2017 Feb;65:289-295. [doi: [10.1016/j.addbeh.2016.08.019](https://doi.org/10.1016/j.addbeh.2016.08.019)] [Medline: [27568339](https://pubmed.ncbi.nlm.nih.gov/27568339/)]
79. Meng H, Kath S, Li D, Nguyen QC. National substance use patterns on Twitter. *PLoS One* 2017;12(11):e0187691 [FREE Full text] [doi: [10.1371/journal.pone.0187691](https://doi.org/10.1371/journal.pone.0187691)] [Medline: [29107961](https://pubmed.ncbi.nlm.nih.gov/29107961/)]
80. Daniulaityte R, Chen L, Lamy FR, Carlson RG, Thirunarayan K, Sheth A. "When 'Bad' is 'Good'": Identifying personal communication and sentiment in drug-related tweets. *JMIR Public Health Surveill* 2016 Oct 24;2(2):e162 [FREE Full text] [doi: [10.2196/publichealth.6327](https://doi.org/10.2196/publichealth.6327)] [Medline: [27777215](https://pubmed.ncbi.nlm.nih.gov/27777215/)]
81. Sarker A, O'Connor K, Ginn R, Scotch M, Smith K, Malone D, et al. Social media mining for toxicovigilance: Automatic monitoring of prescription medication abuse from Twitter. *Drug Saf* 2016 Mar;39(3):231-240 [FREE Full text] [doi: [10.1007/s40264-015-0379-4](https://doi.org/10.1007/s40264-015-0379-4)] [Medline: [26748505](https://pubmed.ncbi.nlm.nih.gov/26748505/)]

82. Crocarno C, Viviani M, Bartoli F, Carrà G, Pasi G. Detecting binge drinking and alcohol-related risky behaviours from Twitter's users: An exploratory content- and topology-based analysis. *Int J Environ Res Public Health* 2020 Feb 26;17(5):1510 [FREE Full text] [doi: [10.3390/ijerph17051510](https://doi.org/10.3390/ijerph17051510)] [Medline: [32111047](https://pubmed.ncbi.nlm.nih.gov/32111047/)]
83. Giorgi S, Yaden DB, Eichstaedt JC, Ashford RD, Buffone AE, Schwartz HA, et al. Cultural differences in Tweeting about drinking across the US. *Int J Environ Res Public Health* 2020 Feb 11;17(4):1125 [FREE Full text] [doi: [10.3390/ijerph17041125](https://doi.org/10.3390/ijerph17041125)] [Medline: [32053866](https://pubmed.ncbi.nlm.nih.gov/32053866/)]
84. Jelodar H, Wang Y, Rabbani M, Xiao G, Zhao R. A collaborative framework based for semantic patients-behavior analysis and highlight topics discovery of alcoholic beverages in online healthcare forums. *J Med Syst* 2020 Apr 07;44(5):101. [doi: [10.1007/s10916-020-01547-0](https://doi.org/10.1007/s10916-020-01547-0)] [Medline: [32266484](https://pubmed.ncbi.nlm.nih.gov/32266484/)]
85. Parackal M, Parackal S, Mather D, Eusebius S. Dynamic transactional model: A framework for communicating public health messages via social media. *Perspect Public Health* 2020 Jul 14:1. [doi: [10.1177/1757913920935910](https://doi.org/10.1177/1757913920935910)] [Medline: [32660353](https://pubmed.ncbi.nlm.nih.gov/32660353/)]
86. Cohn AM, Amato MS, Zhao K, Wang X, Cha S, Pearson JL, et al. Discussions of alcohol use in an online social network for smoking cessation: Analysis of topics, sentiment, and social network centrality. *Alcohol Clin Exp Res* 2019 Jan;43(1):108-114 [FREE Full text] [doi: [10.1111/acer.13906](https://doi.org/10.1111/acer.13906)] [Medline: [30326140](https://pubmed.ncbi.nlm.nih.gov/30326140/)]
87. ElTayeby O, Eaglin T, Abdullah M, Burlinson D, Dou W, Yao L. A feasibility study on identifying drinking-related contents in Facebook through mining heterogeneous data. *Health Informatics J* 2019 Dec;25(4):1756-1767 [FREE Full text] [doi: [10.1177/1460458218798084](https://doi.org/10.1177/1460458218798084)] [Medline: [30230403](https://pubmed.ncbi.nlm.nih.gov/30230403/)]
88. Golbeck J. Predicting alcoholism recovery from Twitter. In: *Proceedings of the 11th International Conference on Social Computing, Behavioral-Cultural Modeling and Prediction and Behavior Representation in Modeling and Simulation*. Cham, Switzerland: Springer; 2018 Presented at: 11th International Conference on Social Computing, Behavioral-Cultural Modeling and Prediction and Behavior Representation in Modeling and Simulation; July 10-13, 2018; Washington, DC p. 243-252 URL: https://doi.org/10.1007/978-3-319-93372-6_28 [doi: [10.1007/978-3-319-93372-6_28](https://doi.org/10.1007/978-3-319-93372-6_28)]
89. Kornfield R, Toma CL, Shah DV, Moon TJ, Gustafson DH. What do you say before you relapse? How language use in a peer-to-peer online discussion forum predicts risky drinking among those in recovery. *Health Commun* 2018 Sep;33(9):1184-1193 [FREE Full text] [doi: [10.1080/10410236.2017.1350906](https://doi.org/10.1080/10410236.2017.1350906)] [Medline: [28792228](https://pubmed.ncbi.nlm.nih.gov/28792228/)]
90. Carah N, Meurk C, Angus D. Online self-expression and experimentation as 'reflectivism': Using text analytics to examine the participatory forum Hello Sunday Morning. *Health (London)* 2017 Mar;21(2):119-135. [doi: [10.1177/1363459315596799](https://doi.org/10.1177/1363459315596799)] [Medline: [26216897](https://pubmed.ncbi.nlm.nih.gov/26216897/)]
91. Cohn AM, Zhao K, Cha S, Wang X, Amato MS, Pearson JL, et al. A descriptive study of the prevalence and typology of alcohol-related posts in an online social network for smoking cessation. *J Stud Alcohol Drugs* 2017 Sep;78(5):665-673 [FREE Full text] [doi: [10.15288/jsad.2017.78.665](https://doi.org/10.15288/jsad.2017.78.665)] [Medline: [28930053](https://pubmed.ncbi.nlm.nih.gov/28930053/)]
92. Liu J, Weitzman E, Chunara R. Assessing behavioral stages from social media data. In: *Proceedings of the 2017 ACM Conference on Computer Supported Cooperative Work and Social Computing*. New York, NY: Association for Computing Machinery; 2017 Presented at: 2017 ACM Conference on Computer Supported Cooperative Work and Social Computing; February 25-March 1, 2017; Portland, OR p. 1320-1333 URL: <http://europepmc.org/abstract/MED/29034371> [doi: [10.1145/2998181.2998336](https://doi.org/10.1145/2998181.2998336)]
93. Parackal M, Parackal S, Eusebius S, Mather D. The use of Facebook advertising for communicating public health messages: A campaign against drinking during pregnancy in New Zealand. *JMIR Public Health Surveill* 2017 Aug 10;3(3):e49 [FREE Full text] [doi: [10.2196/publichealth.7032](https://doi.org/10.2196/publichealth.7032)] [Medline: [28798011](https://pubmed.ncbi.nlm.nih.gov/28798011/)]
94. Cesare N, Nguyen QC, Grant C, Nsoesie EO. Social media captures demographic and regional physical activity. *BMJ Open Sport Exerc Med* 2019;5(1):e000567 [FREE Full text] [doi: [10.1136/bmjsem-2019-000567](https://doi.org/10.1136/bmjsem-2019-000567)] [Medline: [31423323](https://pubmed.ncbi.nlm.nih.gov/31423323/)]
95. Nguyen QC, Li D, Meng H, Kath S, Nsoesie E, Li F, et al. Building a national neighborhood dataset from geotagged Twitter data for indicators of happiness, diet, and physical activity. *JMIR Public Health Surveill* 2016 Oct 17;2(2):e158 [FREE Full text] [doi: [10.2196/publichealth.5869](https://doi.org/10.2196/publichealth.5869)] [Medline: [27751984](https://pubmed.ncbi.nlm.nih.gov/27751984/)]
96. Yoon S, Elhadad N, Bakken S. A practical approach for content mining of tweets. *Am J Prev Med* 2013 Jul;45(1):122-129 [FREE Full text] [doi: [10.1016/j.amepre.2013.02.025](https://doi.org/10.1016/j.amepre.2013.02.025)] [Medline: [23790998](https://pubmed.ncbi.nlm.nih.gov/23790998/)]
97. Liu Y, Yin Z. Understanding weight loss via online discussions: Content analysis of Reddit posts using topic modeling and word clustering techniques. *J Med Internet Res* 2020 Jun 08;22(6):e13745 [FREE Full text] [doi: [10.2196/13745](https://doi.org/10.2196/13745)] [Medline: [32510460](https://pubmed.ncbi.nlm.nih.gov/32510460/)]
98. Liang B, Wang Y, Tsou M. A "fitness" theme may mitigate regional prevalence of overweight and obesity: Evidence from Google search and tweets. *J Health Commun* 2019;24(9):683-692. [doi: [10.1080/10810730.2019.1657526](https://doi.org/10.1080/10810730.2019.1657526)] [Medline: [31469057](https://pubmed.ncbi.nlm.nih.gov/31469057/)]
99. Ghosh D, Guha R. What are we 'tweeting' about obesity? Mapping tweets with topic modeling and geographic information system. *Cartogr Geogr Inf Sci* 2013;40(2):90-102 [FREE Full text] [doi: [10.1080/15230406.2013.776210](https://doi.org/10.1080/15230406.2013.776210)] [Medline: [25126022](https://pubmed.ncbi.nlm.nih.gov/25126022/)]
100. Shah N, Srivastava G, Savage DW, Mago V. Assessing Canadians' health activity and nutritional habits through social media. *Front Public Health* 2020;7:400 [FREE Full text] [doi: [10.3389/fpubh.2019.00400](https://doi.org/10.3389/fpubh.2019.00400)] [Medline: [31993412](https://pubmed.ncbi.nlm.nih.gov/31993412/)]

101. Park A, Conway M. Tracking health related discussions on Reddit for public health applications. *AMIA Annu Symp Proc* 2018;2017:1362-1371 [FREE Full text] [Medline: 29854205]
102. Huang T, Elghafari A, Relia K, Chunara R. High-resolution temporal representations of alcohol and tobacco behaviors from social media data. *Proc ACM Hum Comput Interact* 2017 Nov;1(CSCW):54 [FREE Full text] [doi: 10.1145/3134689] [Medline: 29264592]
103. Tamersoy A, De Choudhury M, Chau D. Characterizing smoking and drinking abstinence from social media. In: *Proceedings of the 26th ACM Conference on Hypertext and Social Media*. New York, NY: Association for Computing Machinery; 2015 Presented at: 26th ACM Conference on Hypertext and Social Media; September 1-4, 2015; Guzelyurt, Cyprus p. 139-148 URL: <http://europepmc.org/abstract/MED/26640831> [doi: 10.1145/2700171.2791247]
104. Twitter API. Twitter Developer. URL: <https://developer.twitter.com/en/docs/twitter-api> [accessed 2020-10-02]
105. APIs and SDKs. Facebook for Developers. URL: <https://developers.facebook.com/docs/apis-and-sdks/> [accessed 2020-10-02]
106. Instagram basic display API. Facebook for Developers. URL: <https://developers.facebook.com/docs/instagram-basic-display-api/> [accessed 2020-10-02]
107. reddit API documentation. reddit. URL: <https://www.reddit.com/dev/api/> [accessed 2020-10-02]
108. Zhang Y, Allem J, Unger JB, Boley Cruz T. Automated identification of hookahs (waterpipes) on Instagram: An application in feature extraction using convolutional neural network and support vector machine classification. *J Med Internet Res* 2018 Nov 21;20(11):e10513 [FREE Full text] [doi: 10.2196/10513] [Medline: 30452385]
109. Ketonen V, Malik A. Characterizing vaping posts on Instagram by using unsupervised machine learning. *Int J Med Inform* 2020 Sep;141:104223 [FREE Full text] [doi: 10.1016/j.ijmedinf.2020.104223] [Medline: 32623330]
110. Tausczik YR, Pennebaker JW. The psychological meaning of words: LIWC and computerized text analysis methods. *J Lang Soc Psychol* 2009 Dec 08;29(1):24-54. [doi: 10.1177/0261927X09351676]
111. Blei D, Ng A, Jordan M. Latent Dirichlet allocation. *J Mach Learn Res* 2003 Mar;3:993-1022 [FREE Full text]
112. Bastian M, Heymann S, Jacomy M. Gephi: an open source software for exploring and manipulating networks. *Icswm* 2009;8(2009):361-362.
113. Borgatti S, Everett M, Freeman L. UCINET for Windows: Software for social network analysis. Google Sites. Harvard, MA: Analytic Technologies; 2002. URL: <https://sites.google.com/site/ucinetsoftware/home> [accessed 2020-11-21]
114. Myneni S, Iyengar S. Socially influencing technologies for health promotion: Translating social media analytics into consumer-facing health solutions. In: *Proceedings of the 49th Hawaii International Conference on System Sciences (HICSS)*. New York, NY: IEEE; 2016 Presented at: 49th Hawaii International Conference on System Sciences (HICSS); January 5-8, 2016; Koloa, HI p. 3084-3093. [doi: 10.1109/HICSS.2016.388]
115. Yardley L, Spring BJ, Riper H, Morrison LG, Crane DH, Curtis K, et al. Understanding and promoting effective engagement with digital behavior change interventions. *Am J Prev Med* 2016 Nov;51(5):833-842. [doi: 10.1016/j.amepre.2016.06.015] [Medline: 27745683]
116. Barnlund DC. A transactional model of communication. In: Sereno KK, Mortensen CD, editors. *Foundations of Communication Theory*. New York, NY: Harper and Row; 1970:99.
117. Bandura A. *Social Foundations of Thought and Action: A Social Cognitive Theory*. Englewood Cliffs, NJ: Prentice-Hall; 1986.
118. Prochaska JO, Velicer WF. The transtheoretical model of health behavior change. *Am J Health Promot* 1997;12(1):38-48. [doi: 10.4278/0890-1171-12.1.38] [Medline: 10170434]
119. Sheeran P, Abraham C. The health belief model. In: Ayers S, Baum A, McManus C, Newman S, Wallston K, Weinman J, et al, editors. *Cambridge Handbook of Psychology, Health and Medicine*. 2nd edition. Cambridge, UK: Cambridge University Press; 2007:97-102.
120. Abraham C, Michie S. A taxonomy of behavior change techniques used in interventions. *Health Psychol* 2008 May;27(3):379-387. [doi: 10.1037/0278-6133.27.3.379] [Medline: 18624603]
121. Michie S, Yardley L, West R, Patrick K, Greaves F. Developing and evaluating digital interventions to promote behavior change in health and health care: Recommendations resulting from an international workshop. *J Med Internet Res* 2017 Jun 29;19(6):e232 [FREE Full text] [doi: 10.2196/jmir.7126] [Medline: 28663162]
122. Riley WT, Rivera DE, Atienza AA, Nilsen W, Allison SM, Mermelstein R. Health behavior models in the age of mobile interventions: Are our theories up to the task? *Transl Behav Med* 2011 Mar;1(1):53-71 [FREE Full text] [doi: 10.1007/s13142-011-0021-7] [Medline: 21796270]
123. Chou WS, Oh A, Klein WMP. Addressing health-related misinformation on social media. *JAMA* 2018 Dec 18;320(23):2417-2418. [doi: 10.1001/jama.2018.16865] [Medline: 30428002]
124. Allington D, Duffy B, Wessely S, Dhavan N, Rubin J. Health-protective behaviour, social media usage and conspiracy belief during the COVID-19 public health emergency. *Psychol Med* 2020 Jun 09;1-7 [FREE Full text] [doi: 10.1017/S003329172000224X] [Medline: 32513320]
125. Tasnim S, Hossain MM, Mazumder H. Impact of rumors and misinformation on COVID-19 in social media. *J Prev Med Public Health* 2020 May;53(3):171-174 [FREE Full text] [doi: 10.3961/jpmph.20.094] [Medline: 32498140]
126. Allem J, Ferrara E. The importance of debiasing social media data to better understand e-cigarette-related attitudes and behaviors. *J Med Internet Res* 2016 Aug 09;18(8):e219 [FREE Full text] [doi: 10.2196/jmir.6185] [Medline: 27507563]

127. Albarracin D, Romer D, Jones C, Hall Jamieson K, Jamieson P. Misleading claims about tobacco products in YouTube videos: Experimental effects of misinformation on unhealthy attitudes. *J Med Internet Res* 2018 Jun 29;20(6):e229 [FREE Full text] [doi: [10.2196/jmir.9959](https://doi.org/10.2196/jmir.9959)] [Medline: [29959113](https://pubmed.ncbi.nlm.nih.gov/29959113/)]
128. Salimian PK, Chunara R, Weitzman ER. Averting the perfect storm: Addressing youth substance use risk from social media use. *Pediatr Ann* 2014 Oct;43(10):411. [doi: [10.3928/00904481-20140924-08](https://doi.org/10.3928/00904481-20140924-08)] [Medline: [25290130](https://pubmed.ncbi.nlm.nih.gov/25290130/)]
129. Mamidi R, Miller M, Banerjee T, Romine W, Sheth A. Identifying key topics bearing negative sentiment on Twitter: Insights concerning the 2015-2016 Zika epidemic. *JMIR Public Health Surveill* 2019 Jun 04;5(2):e11036 [FREE Full text] [doi: [10.2196/11036](https://doi.org/10.2196/11036)] [Medline: [31165711](https://pubmed.ncbi.nlm.nih.gov/31165711/)]
130. Stevens R, Bonett S, Bannon J, Chittamuru D, Slaff B, Browne SK, et al. Association between HIV-related tweets and HIV incidence in the United States: Infodemiology study. *J Med Internet Res* 2020 Jun 24;22(6):e17196 [FREE Full text] [doi: [10.2196/17196](https://doi.org/10.2196/17196)] [Medline: [32579119](https://pubmed.ncbi.nlm.nih.gov/32579119/)]
131. Myneni S, Lewis B, Singh T, Paiva K, Kim SM, Cebula AV, et al. Diabetes self-management in the age of social media: Large-scale analysis of peer interactions using semiautomated methods. *JMIR Med Inform* 2020 Jun 30;8(6):e18441 [FREE Full text] [doi: [10.2196/18441](https://doi.org/10.2196/18441)] [Medline: [32602843](https://pubmed.ncbi.nlm.nih.gov/32602843/)]
132. Singh T, Wang J, Myneni S. Revealing intention in health-related peer interactions: Implications for optimizing patient engagement in self-health management. In: Proceedings of the AMIA 2020 Virtual Annual Symposium. 2020 Presented at: AMIA 2020 Virtual Annual Symposium; November 14-18, 2020; Virtual.
133. Xu C, Yang H, Sun L, Cao X, Hou Y, Cai Q, et al. Detecting lung cancer trends by leveraging real-world and internet-based data: Infodemiology study. *J Med Internet Res* 2020 Mar 12;22(3):e16184 [FREE Full text] [doi: [10.2196/16184](https://doi.org/10.2196/16184)] [Medline: [32163035](https://pubmed.ncbi.nlm.nih.gov/32163035/)]
134. Chen L, Lu X, Yuan J, Luo J, Luo J, Xie Z, et al. A social media study on the associations of flavored electronic cigarettes with health symptoms: Observational study. *J Med Internet Res* 2020 Jun 22;22(6):e17496 [FREE Full text] [doi: [10.2196/17496](https://doi.org/10.2196/17496)] [Medline: [32568093](https://pubmed.ncbi.nlm.nih.gov/32568093/)]
135. Hua M, Sadah S, Hristidis V, Talbot P. Health effects associated with electronic cigarette use: Automated mining of online forums. *J Med Internet Res* 2020 Jan 03;22(1):e15684 [FREE Full text] [doi: [10.2196/15684](https://doi.org/10.2196/15684)] [Medline: [31899452](https://pubmed.ncbi.nlm.nih.gov/31899452/)]
136. Kim AE, Hopper T, Simpson S, Nonnemaker J, Lieberman AJ, Hansen H, et al. Using Twitter data to gain insights into e-cigarette marketing and locations of use: An infoveillance study. *J Med Internet Res* 2015 Nov 06;17(11):e251 [FREE Full text] [doi: [10.2196/jmir.4466](https://doi.org/10.2196/jmir.4466)] [Medline: [26545927](https://pubmed.ncbi.nlm.nih.gov/26545927/)]
137. Struik LL, Dow-Fleisner S, Belliveau M, Thompson D, Janke R. Tactics for drawing youth to vaping: Content analysis of electronic cigarette advertisements. *J Med Internet Res* 2020 Aug 14;22(8):e18943 [FREE Full text] [doi: [10.2196/18943](https://doi.org/10.2196/18943)] [Medline: [32663163](https://pubmed.ncbi.nlm.nih.gov/32663163/)]
138. Kim K, Gibson L, Williams S, Kim Y, Binns S, Emery SL, et al. Valence of media coverage about electronic cigarettes and other tobacco products from 2014 to 2017: Evidence from automated content analysis. *Nicotine Tob Res* 2020 Oct 08;22(10):1891-1900. [doi: [10.1093/ntr/ntaa090](https://doi.org/10.1093/ntr/ntaa090)] [Medline: [32428214](https://pubmed.ncbi.nlm.nih.gov/32428214/)]
139. Ayers JW, Dredze M, Leas EC, Caputi TL, Allem J, Cohen JE. Next generation media monitoring: Global coverage of electronic nicotine delivery systems (electronic cigarettes) on Bing, Google and Twitter, 2013-2018. *PLoS One* 2018;13(11):e0205822 [FREE Full text] [doi: [10.1371/journal.pone.0205822](https://doi.org/10.1371/journal.pone.0205822)] [Medline: [30388126](https://pubmed.ncbi.nlm.nih.gov/30388126/)]
140. Lazard AJ, Wilcox GB, Tuttle HM, Glowacki EM, Pikowski J. Public reactions to e-cigarette regulations on Twitter: A text mining analysis. *Tob Control* 2017 Dec;26(e2):e112-e116. [doi: [10.1136/tobaccocontrol-2016-053295](https://doi.org/10.1136/tobaccocontrol-2016-053295)] [Medline: [28341768](https://pubmed.ncbi.nlm.nih.gov/28341768/)]
141. Harris JK, Moreland-Russell S, Choucair B, Mansour R, Staub M, Simmons K. Tweeting for and against public health policy: Response to the Chicago Department of Public Health's electronic cigarette Twitter campaign. *J Med Internet Res* 2014 Oct 16;16(10):e238 [FREE Full text] [doi: [10.2196/jmir.3622](https://doi.org/10.2196/jmir.3622)] [Medline: [25320863](https://pubmed.ncbi.nlm.nih.gov/25320863/)]
142. E-collection 'Infodemiology and Infoveillance'. JMIR. URL: <https://www.jmir.org/themes/69> [accessed 2020-11-22]
143. Lu X, Chen L, Yuan J, Luo J, Luo J, Xie Z, et al. User perceptions of different electronic cigarette flavors on social media: Observational study. *J Med Internet Res* 2020 Jun 24;22(6):e17280 [FREE Full text] [doi: [10.2196/17280](https://doi.org/10.2196/17280)] [Medline: [32579123](https://pubmed.ncbi.nlm.nih.gov/32579123/)]
144. Allem J, Uppu SP, Boley Cruz T, Unger JB. Characterizing Swisher little cigar-related posts on Twitter in 2018: Text analysis. *J Med Internet Res* 2019 Jul 19;21(7):e14398 [FREE Full text] [doi: [10.2196/14398](https://doi.org/10.2196/14398)] [Medline: [31325291](https://pubmed.ncbi.nlm.nih.gov/31325291/)]
145. Liu S, Chen B, Kuo A. Monitoring physical activity levels using Twitter data: Infodemiology study. *J Med Internet Res* 2019 Jun 03;21(6):e12394 [FREE Full text] [doi: [10.2196/12394](https://doi.org/10.2196/12394)] [Medline: [31162126](https://pubmed.ncbi.nlm.nih.gov/31162126/)]
146. Li Q, Wang C, Liu R, Wang L, Zeng DD, Leischow SJ. Understanding users' vaping experiences from social media: Initial study using sentiment opinion summarization techniques. *J Med Internet Res* 2018 Aug 15;20(8):e252 [FREE Full text] [doi: [10.2196/jmir.9373](https://doi.org/10.2196/jmir.9373)] [Medline: [30111530](https://pubmed.ncbi.nlm.nih.gov/30111530/)]
147. Rose SW, Jo CL, Binns S, Buenger M, Emery S, Ribisl KM. Perceptions of menthol cigarettes among Twitter users: Content and sentiment analysis. *J Med Internet Res* 2017 Feb 27;19(2):e56 [FREE Full text] [doi: [10.2196/jmir.5694](https://doi.org/10.2196/jmir.5694)] [Medline: [28242592](https://pubmed.ncbi.nlm.nih.gov/28242592/)]

148. Zhan Y, Liu R, Li Q, Leischow SJ, Zeng DD. Identifying topics for e-cigarette user-generated contents: A case study from multiple social media platforms. *J Med Internet Res* 2017 Jan 20;19(1):e24 [FREE Full text] [doi: [10.2196/jmir.5780](https://doi.org/10.2196/jmir.5780)] [Medline: [28108428](https://pubmed.ncbi.nlm.nih.gov/28108428/)]
149. Hanson CL, Cannon B, Burton S, Giraud-Carrier C. An exploration of social circles and prescription drug abuse through Twitter. *J Med Internet Res* 2013 Sep 06;15(9):e189 [FREE Full text] [doi: [10.2196/jmir.2741](https://doi.org/10.2196/jmir.2741)] [Medline: [24014109](https://pubmed.ncbi.nlm.nih.gov/24014109/)]

Abbreviations

A-CHESS: Addiction–Comprehensive Health Enhancement Support System
API: application programming interface
AUROC: area under the receiver operating characteristics
CNN: convolutional neural network
DT: decision tree
GloVe: global vectors
ISEAR: International Survey on Emotion Antecedents and Reactions
KNN: k-nearest neighbors
LDA: latent Dirichlet allocation
LIWC: linguistic inquiry word count
LR: logistic regression
LSA: latent semantic analysis
LSTM: long short-term memory
MeSH: Medical Subject Headings
ML: machine learning
PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses
RF: random forest
RI: random indexing
SemEval: semantic evaluation
SentiWords: sentiment words
SGNS: skip-gram with negative sampling
SHAP: SHapley Additive exPlanations
SMAaRT: social media as a research tool
SVM: support vector machine
TASA: Touchstone Applied Science Associates
VADER: Valence Aware Dictionary for sEntiment Reasoning

Edited by T Sanchez; submitted 20.06.20; peer-reviewed by O El-Gayar, JP Allem; comments to author 11.07.20; revised version received 05.10.20; accepted 06.11.20; published 30.11.20.

Please cite as:

Singh T, Roberts K, Cohen T, Cobb N, Wang J, Fujimoto K, Myneni S
Social Media as a Research Tool (SMAaRT) for Risky Behavior Analytics: Methodological Review
JMIR Public Health Surveill 2020;6(4):e21660
URL: <http://publichealth.jmir.org/2020/4/e21660/>
doi: [10.2196/21660](https://doi.org/10.2196/21660)
PMID: [33252345](https://pubmed.ncbi.nlm.nih.gov/33252345/)

©Tavleen Singh, Kirk Roberts, Trevor Cohen, Nathan Cobb, Jing Wang, Kayo Fujimoto, Sahiti Myneni. Originally published in *JMIR Public Health and Surveillance* (<http://publichealth.jmir.org>), 30.11.2020. This is an open-access article distributed under the terms of the Creative Commons Attribution License (<https://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in *JMIR Public Health and Surveillance*, is properly cited. The complete bibliographic information, a link to the original publication on <http://publichealth.jmir.org>, as well as this copyright and license information must be included.

Original Paper

How Internet Contracts Impact Research: Content Analysis of Terms of Service on Consumer Product Websites

Caitlin Weiger¹, MHS; Katherine C Smith², PhD; Joanna E Cohen², PhD; Mark Dredze³, PhD; Meghan Bridgid Moran¹, PhD

¹Department of Health, Behavior & Society, Johns Hopkins Bloomberg School of Public Health, Baltimore, MD, United States

²Institute for Global Tobacco Control, Department of Health, Behavior & Society, Johns Hopkins Bloomberg School of Public Health, Baltimore, MD, United States

³Department of Computer Science, Johns Hopkins University, Baltimore, MD, United States

Corresponding Author:

Caitlin Weiger, MHS

Department of Health, Behavior & Society

Johns Hopkins Bloomberg School of Public Health

615 N Wolfe St

Baltimore, MD, 21205

United States

Phone: 1 (410) 955 3543

Email: cweiger2@jhmi.edu

Abstract

Background: Companies use brand websites as a promotional tool to engage consumers on the web, which can increase product use. Given that some products are harmful to the health of consumers, it is important for marketing associated with these products to be subject to public health surveillance. However, terms of service (TOS) governing the use of brand website content may impede such important research.

Objective: The aim of this study is to explore the TOS for brand websites with public health significance to assess possible legal and ethical challenges for conducting research on consumer product websites.

Methods: Using Statista, we purposefully constructed a sample of 15 leading American tobacco, alcohol, psychiatric pharmaceutical, fast-food, and gun brands that have associated websites. We developed and implemented a structured coding system for the TOS on these websites and coded for the presence versus absence of different types of restriction that might impact the ability to conduct research.

Results: All TOS stated that by accessing the website, users agreed to abide by the TOS (15/15, 100%). A total of 11 out of 15 (73%) websites had age restrictions in their TOS. All alcohol brand websites (5/15, 33%) required users to enter their age or date of birth before viewing website content. Both websites for tobacco brands (2/15, 13%) further required that users register and verify their age and identity to access any website content and agree that they use tobacco products. Only one website (1/15, 7%) allowed users to display, download, copy, distribute, and translate the website content as long as it was for personal and not commercial use. A total of 33% (5/15) of TOS unconditionally prohibited or put substantial restrictions on all of these activities and/or failed to specify if they were allowed or prohibited. Moreover, 87% (13/15) of TOS indicated that website access could be restricted at any time. A total of 73% (11/15) of websites specified that violating TOS could result in deleting user content from the website, revoking access by having the user's Internet Protocol address blocked, terminating log-in credentials, or enforcing legal action resulting in civil or criminal penalties.

Conclusions: TOS create complications for public health surveillance related to e-marketing on brand websites. Recent court opinions have reduced the risk of federal criminal charges for violating TOS on public websites, but this risk remains unclear for private websites. The public health community needs to establish standards to guide and protect researchers from the possibility of legal repercussions related to such efforts.

(*JMIR Public Health Surveill* 2020;6(4):e23579) doi:[10.2196/23579](https://doi.org/10.2196/23579)

KEYWORDS

marketing; contracts; internet; jurisprudence; ethics

Introduction

Background

A growing proportion of morbidity and mortality globally can be attributed to the commercialization of products that are harmful to health. Products such as tobacco, alcohol, fast food, and firearms account for an increasing proportion of preventable deaths, a trend referred to as the *industrial epidemic* [1]. For example, globally, there were 2.8 million deaths associated with alcohol consumption and over 8.1 million deaths associated with tobacco consumption in 2017 [2]. Dietary risk factors (including diets high in sodium, low in vegetables, low in fruit, low in whole grains, low in nuts and seeds, and low in seafood omega-3) caused 10.9 million deaths in 2017 [2]. In the United States alone, in 2015, firearms were responsible for over 36,000 deaths [3] and caused 612,000 deaths between 1999 and 2017 [4].

The industries that manufacture these products continue to rely heavily on marketing to attract and retain consumers to maintain and grow their profit margins; these actions contribute to the overall burden of disease caused by their products [5]. Although estimates of the marketing expenditures of the firearms industry are not currently available, tobacco, alcohol, and fast-food companies spend billions, often tens of billions of dollars, on advertising each year [6-9]. There is substantial evidence to suggest that exposure to tobacco, alcohol, food, and firearm marketing increases the desire to use, intentions to use, and/or actual use of advertised products [8,10-27]. Children and adolescents are particularly susceptible to advertising and promotional efforts, given their developmental stage, and are more likely to adopt attitudes and preferences congruent with advertisements after exposure [28]. In instances where products can have detrimental effects on health, advertising becomes a major public health concern.

The research literature on marketing practices for potentially harmful products at the point of sale, on television, and in print media is longstanding and robust [8,13,21,23,24,26,29-31]. The placement of advertising and promotional efforts is, however, increasingly dominated by the web-based domain [32], which provides the possibility of reaching more than 4.5 billion people in the world with internet access [33]. Companies are transferring traditional marketing principles to the internet as *e-marketing* by using websites, social media, and web-based marketplaces to increase connections with potential customers.

Advertising on brand websites has already started to attract the attention of researchers. Research on alcohol brand websites, for example, has documented strategies that utilize youth culture, including computer games, competitions, downloadable content, sponsored parties, fashion shows, and sporting events [34]. Tobacco internet marketing has also been highlighted as a surveillance priority [35]. Descriptive research has found that tobacco brand websites offer sweepstakes; event promotions; video advertising; and contests involving music creation, lyric writing, creative design, and other arts to engage users on the web [36-39]. Food and beverage websites have been found to contain *gamified* content that is designed specifically for children and often includes games that highlight branded content

(adver-games), branded downloadable content, viral content, and unlimited commercials [40-42]. However, no research has assessed the marketing content of gun websites, although recent research characterizing firearm advertising on Twitter and YouTube has been published [43]. Both firearm manufacturers and social media influencers on these platforms promoted guns for recreational and military use, and used patriotic and law enforcement themes. Importantly, this research also revealed that social media posts, particularly YouTube posts, often connect viewers to firearm manufacturer websites [43]. Previous research has established that brand websites are filled with promotions and advertising strategies meant to interactively engage users in a way that is not possible with print media or even television commercials.

The use of e-marketing is also potentially problematic because it is more difficult for regulatory authorities to monitor and regulate web-based space, resulting in less oversight [44,45]. The enforcement guidelines of the Food and Drug Administration (FDA) for the 2010 Tobacco Control Act states that it will conduct surveillance of internet promotions to ensure compliance with advertising and promotion restrictions, although it is unclear how this is carried out in light of terms of service (TOS) and authorization restrictions [46]. It is possible that companies are taking advantage of the less regulated web-based world to employ more aggressive advertising strategies that are already restricted in other media. For instance, researchers have found that some content on UK alcohol brand websites may violate UK broadcasting codes because of the likelihood that it would appeal to underage consumers [47]. There is a need for regulatory authorities to ensure that there is no gap in oversight of web-based commercial spaces. Surveillance has been referred to as the foundation of public health [48], and monitoring and curtailing advertising of potentially harmful and intrinsically harmful products is an important aspect of public health practice.

E-marketing, although clearly a source of concern for public health, poses challenges for researchers. Websites are the property of corporations that draft TOS that can legally shape how site users are allowed to engage with content. The *Law Dictionary* defines terms and conditions (abbreviated TOS) as “Special and general arrangement, rule, requirements, standards, etc. Forming integral parts of a contract or agreement” [49]. Website TOS typically take on 2 forms: click-wrap agreements and browse-wrap agreements. Click-wrap agreements require that the user clicks a box or otherwise actively indicates that he or she assents to the TOS before he or she is able to access website content [50]. Browse-wrap agreements, on the other hand, do not require the user to actively agree to the TOS. Instead, the TOS are located somewhere on the web page, which is usually accessible by a link at the bottom of the page. Courts have ruled inconsistently regarding whether TOS legally constitute notice, which is required for a contract to be binding, although click-wrap agreements have been upheld more routinely than browse-wrap agreements [51-55]. The legally ambiguous nature of TOS makes it unclear if the prohibitions often outlined in these terms are legally binding, and research has shown that they are rarely read or understood [56-58].

Frischmann and Selinger [59] maintained that the length and complexity of TOS are intentional design features. They

described TOS contracts as “techno-social tools for engineering human beings to behave automatically, like simple machines.” TOS contracts are *take-it-or-leave-it* contracts, where users can either accept terms or not access the website. This means that website users gain nothing by reading many pages of legal jargon, as they have no power to change the terms of the contract, and are able to reduce the cognitive cost of the encounter by ignoring TOS [59]. Frischmann and Selinger [59] state that website designers function as *choice architects* by shaping the choices that users are presented with and that TOS are subject to this design influence as much as website content is. As the choice regarding TOS is to accept the TOS or not use the website, unthinking, constant acceptance becomes the norm as people become *programmed* to agree [59]. Legal scholar Margaret Jane Radin additionally raises concerns regarding *boilerplate creep*, where private entities, such as corporations, gradually replace law from public spaces such as governments and social institutions with their own *law* that is designed to benefit the private entity rather than the public good [60]. These concerns that TOS are intentionally designed to deflect website user attention and at the same time benefit private entities underlies the importance of better understanding the content of TOS contracts and how they may influence research.

When TOS are actually read, it becomes clear that many activities necessary to conduct research are often restricted. Preliminary exploration found TOS on brand websites that prohibit users, for example, from downloading (eg, saving copies of content for future reference) and sharing material, tasks necessary to conduct research. The terms of entry into web-based spaces designed by corporations are more explicit and seem to hold the potential for greater enforcement in the web-based domain as compared with conditions for entry into retail spaces in the physical environment. The uncertain legal nature of TOS may also impact the comfort level of the researchers who study web-based spaces, and some researchers have expressed fear that this uncertainty might have chilling effects on research [61].

Goal of This Study

Little attention has been paid to establishing appropriate norms for entering web-based spaces for the purpose of understanding the space in and of itself. Although a recent publication [62] discusses the content of TOS on social media websites, focusing on both automated and manual data scraping of user content, conducting research on consumer product websites is somewhat different. Content analyses would not necessitate scraping and do not document user content the way social media research does. TOS on consumer product websites require the same kind of consideration that TOS on social media websites have received. The Association of Computing Machinery, a professional organization for computing scientists, has already started to discuss if it is ethical to violate TOS during the process of data collection of publicly available information [63,64]. The association has even appealed to the court in an *amicus curiae* briefing, arguing that researchers should be legally allowed to conduct research on public web-based spaces [65]. This issue also needs to be considered by public health researchers.

Currently, researchers are leaving themselves potentially vulnerable to legal issues by conducting research that might violate the TOS of websites. Given the public health importance of monitoring product marketing in web-based spaces, in this study, we describe the types of activities that are and are not allowed by TOS across multiple product types and what types of restrictions are being put on website access. We also consider how this might differ by product type and discuss implications of restrictions included in TOS for research and the ethical and legal ramifications of not adhering to TOS, given recent litigation.

Methods

Setting and Sample

We searched Statista, the “statistics portal for market data, market research, and market studies” [66] for the top branded consumer products in 5 domains relevant to public health: tobacco (cigarettes), alcohol (beer and distilled spirits), firearms, prescription psychiatric drugs, and fast food. In addition to the *industrial epidemic* products described earlier, we included prescription drug websites because of the heavy use of direct-to-consumer marketing [67], a practice only allowed in the United States and New Zealand [68], and the association between exposure to this marketing and subsequent desire to use such drugs [17-19]. We choose to focus on psychiatric drugs due to the high prevalence of use among American adults [69]. To identify the top brands in these domains, we searched Statista for the top brands in the United States by market share for each product. When data on market shares by brand were not available, we searched for top brands by revenue from sales. We selected the highest ranked brands that listed the law governing their TOS as a state within the United States and that had an official website. Official websites were defined as websites created by the actual company rather than a fan group or a specific retailer. We restricted our study to US companies that listed a location within the United States as governing their TOS because we wanted to control for some variance in TOS by the country that the company operated in, as regional laws and requirements may differ by country.

For cigarette brands, the 3 US market leaders, Marlboro, Newport, and Camel, were all American companies with official websites created by the company. Marlboro and Newport were selected for the sample. Camel was excluded because both Camel and Newport were owned by R. J. Reynolds Tobacco Company and had the same TOS. Data on US market leaders for beer brands showed that Bud Light and Coors Light occupied the largest portion of the beer market and were retained for the sample. Statista did not have data on distilled spirits as a general category; however, it had existing data on the top whiskey brands by market share, with Jack Daniels, Crown Royal, Fireball, and Jim Beam being the market leaders. The British company Diageo owns Crown Royal and was excluded, whereas Fireball, Jack Daniels, and Jim Beam were retained as US-owned brands. Although Statista did not have data on the top market leaders in the firearms industry, it did provide data on the estimated global revenue for firearms made for the US market, which was used as a proxy for establishing the leading

companies. The top 3 firearm manufacturers—Remington, Smith and Wesson, and Sturm Ruger—are all US companies with official websites and were retained for this sample. Similarly, the top companies producing psychiatric drugs were also determined using Statista data on revenue from top-selling psychiatric drugs in the United States. The top brand, Lyrica, was retained for the sample. The second brand, Vyvanse, stated in its TOS that it is governed by British, rather than American law, and the website was excluded from the sample for this

reason. Invega Sustenna was retained as this brand had an official website, and the jurisdiction listed in its TOS was within the United States. Revenue from sales was also used to determine the top fast-food brands. McDonalds, Starbucks, and Subway were retained for this sample as the jurisdiction listed in their TOS was within the United States, and all the brands had official websites (Table 1). In total, 15 websites were included in the sample.

Table 1. Acquisition of website sampling using data from Statista.

Product type and metric used/Top brands listed	Webcite reference for the brands selected	Date of last TOS ^a update (as of July 2018)	Date of last TOS update (as of July 2020)
Cigarettes, market share of the leading US cigarette brands in 2016 (%)			
Marlboro, 41	[70]	May 2014	May 2014
Newport, 13	[70]	August 17, 2017	August 17, 2017
Camel, 8	— ^b	—	—
Beer, domestic beer market share of the leading brands in the United States in 2017 (%)			
Bud Light, 18	[71]	No date provided	January 1, 2020
Coors Light, 10	[72]	May 22, 2018	January 1, 2020
Whiskey, US market share of the leading whiskey brands in 2017 through 2018, based on dollar sales (%)			
Jack Daniels, 13	[73]	March 15, 2018	March 15, 2018
Crown Royal, 12	—	—	—
Fireball, 8	[74]	June 21, 2017	June 21, 2017
Jim Beam, 8	[75]	October 29, 2008	January 31, 2020
Firearms, estimated global revenue made annually for the US civilian market (million US \$)			
Remington Outdoor, 939	[76]	April 1, 2017	No date provided
Smith and Wesson, 552	[77]	April 1, 2017	June 1, 2020
Sturm Ruger, 551	[78]	September 1, 2010	September 1, 2010
Psychiatric drugs, selected top psychiatric drugs' US revenue in 2016 (million US \$)			
Lyrica, 4.4	[79]	No date provided	No date provided
Vyvanse, 3.1	—	—	—
Invega Sustenna, 1.3	[80]	November 4, 2016	November 4, 2016
Fast food, leading quick service restaurants in the United States in 2016, based on retail sales (billion US \$)			
McDonalds, 36.4	[81]	March 13, 2017	March 13, 2017
Starbucks, 15.8	[82]	October 27, 2017	October 2019
Subway, 14.0	[83]	June 14, 2018	January 1, 2020

^aTOS: terms of service.

^bNot included in the sample.

Official websites for each brand were located by searching the brand name with the word *website* in Google. Each website was opened, and restrictions on website access, such as pop-up windows and registration pages, were documented. The TOS were located, typically by scrolling to the bottom of the website homepage and looking for a link called *terms of service* or some other equivalent. TOS from each website were copied and pasted into Microsoft Word. All TOS were saved to Webcite (with the exception of the Marlboro website TOS, which blocked Webcite

from saving its content) and were also downloaded and saved as PDFs.

Analysis

All TOS were downloaded and coded in Microsoft Word (Word version 16.34) employing line-by-line open coding. After reading the TOS and conducting an initial round of coding for major themes, codes were discussed with the study team at multiple meetings, and codes were added and refined per group discussion (Textbox 1). Codes were developed based on how

specific aspects of TOS could impact research. The primary coder (CW) has considerable experience with both qualitative and quantitative coding. After the primary coder completed coding, 2 additional coders (KS and MM) independently reviewed and confirmed all codes. Discrepancies were discussed

and resolved during email exchanges between the coders and the broader research team. The proportion of websites employing each code was calculated in Microsoft Excel (Excel version 16.37), and differences and themes by product type were qualitatively assessed because of the small sample size.

Textbox 1. Codes that emerged from the qualitative process and corresponding examples.

Age restrictions	<ul style="list-style-type: none"> • ≥ 21 years, legal age of product consumption, ≥ 18 years of age or \geq age of majority, ≥ 13 years with parental consent, ≥ 13 years, or no age restrictions
Other access restrictions	<ul style="list-style-type: none"> • Users must be a user of our product to access this website, and/or users must agree to receive promotional materials
Accepting TOS (terms of service)	<ul style="list-style-type: none"> • By accessing this website, users agree to abide by the TOS (use of all capital letters were sometimes used to emphasize this point)
TOS can change at any time	<ul style="list-style-type: none"> • Users acknowledge that TOS can change at any time, users will be notified of changes to TOS, or users are expected to check TOS for any changes during each website visit
Restrictions on sharing account information	<ul style="list-style-type: none"> • It is the user's responsibility to keep log-in credentials confidential
User information accuracy	<ul style="list-style-type: none"> • All information provided by the user must be accurate
Prohibited and allowable user actions with website material	<ul style="list-style-type: none"> • A series of codes indicating when or if copying, displaying, distributing, downloading, transmitting, translating, and republishing is prohibited or allowed
Applicable local laws	<ul style="list-style-type: none"> • Users agree to abide by applicable local laws while using this website
Choice of law	<ul style="list-style-type: none"> • TOS are interpreted and governed by the laws in, for example, North Carolina
Restrict user access	<ul style="list-style-type: none"> • The company can restrict user access to this website for any reason at any time
Allowable use	<ul style="list-style-type: none"> • Commercial, personal, private, noncommercial, etc
Actions taken if user violates TOS	<ul style="list-style-type: none"> • Having the user's internet protocol address blocked, taking legal action against the user, and/or deleting user content from the website

Results

Access and Restrictions

All tobacco (2/2, 100%) and alcohol (5/5, 100%) websites presented with a pop-up window or a registration page when users first enter the website. Both tobacco websites had registration windows, whereas all 5 alcohol websites had pop-up windows. Pop-ups on alcohol websites only required the user

to input a date of birth or confirm that they were aged ≥ 21 years, with no verification process. Two alcohol websites also asked for geographical location. All but 3 websites (12/15, 80%)—2 firearm websites and 1 pharmaceutical website—explicitly stated an age requirement for user access (Table 2). Both tobacco websites additionally required that registrants be tobacco users, with 1 tobacco website also requiring that users sign up for a mailing list and be willing to receive promotional material. No other websites had additional restrictions apart from age.

Table 2. Number of websites with age restriction on website access.

Product type	Age ≥21 years	Legal age of product consumption	Age ≥18 years	Age ≥13 years with parental consent if under 18 years or the legal age of majority	Age ≥13 years	No age restrictions
Tobacco (n=2), TOS ^a number, n (%)	2 (100)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
Alcohol (n=5), TOS number, n (%)	2 (40)	3 (60)	0 (0)	0 (0)	0 (0)	0 (0)
Pharmaceuticals (n=2), TOS number, n (%)	0 (0)	0 (0)	1 (50)	0 (0)	0 (0)	1 (50)
Fast food (n=3), TOS number, n (%)	0 (0)	0 (0)	0 (0)	3 (100)	0 (0)	0 (0)
Firearms (n=3), TOS number, n (%)	0 (0)	0 (0)	0 (0)	0 (0)	1 (33)	2 (67)

^aTOS: terms of service.

The TOS for 10 websites (10/15, 67%; 2 tobacco, 4 alcohol, 1 pharmaceutical, 2 fast food, and 1 firearm) held users responsible for keeping their log-in credentials (should they create an account) private, and the TOS for 6 websites (6/15, 40%) specified that information used to create an account must be accurate (2 tobacco, 2 alcohol, and 2 food). The Newport TOS, for instance, states, “You must sign-up online to create an account to access and use the Site. You agree not to use any false, inaccurate, or misleading information when signing up

for your accounts.” Newport is also the only website in the sample that specifies that they independently verify that registrants are aged ≥21 years.

All website TOS (15/15, 100%) had language stating that accessing the website required users to accept the TOS, and all but one pharmaceutical company (14/15, 93%) said that the TOS could change at any time and that users may or may not be notified of this fact (Table 3).

Table 3. Accepting terms of service and the possibility of changing terms by accessing websites.

Product type	By accessing the website, users agree to the TOS ^a	TOS can change at any time	The user is responsible for checking the TOS for changes and is bound by the changes	Website will post announcements when the TOS change and users are bound by the changes	Used all capitalization to emphasize that by accessing the website, the user agrees to the TOS
Tobacco (n=2), TOS number, n (%)	2 (100)	2 (100)	1 (50)	1 (50)	0 (0)
Alcohol (n=5), TOS number, n (%)	5 (100)	5 (100)	4 (80)	1 (20)	3 (60)
Pharmaceuticals (n=2), TOS number, n (%)	2 (100)	1 (50)	1 (50)	0 (0)	0 (0)
Fast food (n=3), TOS number, n (%)	3 (100)	3 (100)	2 (67)	1 (33)	1 (33)
Firearms (n=3), TOS number, n (%)	3 (100)	3 (100)	3 (100)	0 (0)	2 (67)

^aTOS: terms of service.

Local Laws, Jurisdiction, and Restricting Access

Language requiring users to comply with applicable local laws in addition to the terms stated in the TOS was common (2 tobacco, 4 alcohol, 1 pharmaceutical, 2 fast food, and 3 firearms; 12/15, 80%). All TOS (15/15, 100%) also specified a state within the United States whose laws would govern and interpret the TOS and serve as a location for any future litigation. Virginia, North Carolina, Missouri, Illinois, Kentucky, New York, New Jersey, Washington, Connecticut, and Massachusetts (10 states) were listed for the 15-website sample used in this study.

With only 2 exceptions (1 pharmaceutical and 1 alcohol; 13/15, 87%), all websites stated that they could revoke a user's access at any time, without providing a justification. A total of 73% (11/15) TOS listed specific consequences for breaking or violating the TOS, including having the user's internet protocol address blocked so they could no longer access the website; pursuing legal action against the user, resulting in civil or criminal penalties; terminating log-in credentials; and deleting

user content from the website (2 tobacco, 3 alcohol, 2 pharmaceutical, 2 fast food, and 2 firearms).

Allowable and Prohibited Actions With Website Content

Each TOS further specified what users were and were not allowed to do with the content of the website. Most of the TOS prohibited using website content for commercial purposes, and all but 3 TOS specified that website material could only be used for personal or individual or noncommercial purposes (1 tobacco, 4 alcohol, 2 pharmaceutical, 2 fast food, and 3 firearms; 12/15, 80%).

Website TOS described specific restrictions on how website content could be used (Table 4). A total of 33% (5/15) TOS unconditionally or near unconditionally prohibited or put substantial restrictions on all of these activities (2 tobacco) and/or failed to specify if they were allowed or prohibited (2 alcohol and 1 food). Substantial restrictions, for instance, were found on the Marlboro website, which stated that there might be instances where users are given explicit permission to use

website content outside of the site, but that this use could only be for personal noncommercial purposes and only applied when users were given explicit permission on the web page. A total of 73% (11/15) websites prohibited distributing website content or required prior permission to distribute materials. Moreover, 53% (8/15) websites allowed users to engage in at least one activity that exceeded simply viewing of website material (eg, download, copy, or distribute) for personal or individual noncommercial purposes and often explicitly stated that downloaded content must retain all copyrights and trademarks and may only be allowed in limited circumstances (4 alcohol,

1 pharmaceutical, 2 fast food, and 1 firearm). The same set of websites also prohibited users from sharing website content with others. One pharmaceutical company also fell into this category but additionally allowed distribution for noncommercial purposes. Many website TOS did not specify if displaying (4/15, 27%), downloading (5/15, 33%), copying (3/15, 20%), and translating (8/15, 53%) website content was allowed. Only 1 website in the sample (Invega Sustenna) allowed users to display, download, copy, distribute, and translate website content as long as it was for personal and not commercial use.

Table 4. Prohibited or allowable use of website content.

Brand name	Display website content	Download website content	Copy website content	Distribute website content	Translate website content
Marlboro	Prohibited	In circumstances where specific sections of the website say you can use website materials offline, it must be for personal noncommercial purposes	Prohibited	Prohibited	Prohibited
Newport	Prohibited	Prohibited (all actions other than viewing are prohibited unless otherwise specified)	Prohibited	Prohibited (all actions other than viewing are prohibited unless otherwise specified)	Prohibited (all actions other than viewing are prohibited unless otherwise specified)
Bud Light	Prohibited without prior permission	Not specified	Prohibited without prior permission	Prohibited without prior permission	Not specified
Coors Light	Not specified	Not specified	Not specified	Prohibited without prior permission	Not specified
Jim Beam	Prohibited without prior permission	Allowed for noncommercial, lawful, and personal use with copyright retained	Prohibited without prior permission	Prohibited without prior permission	Prohibited without prior permission
Jack Daniels	Not specified	Allowable for one copy for personal, noncommercial use with copyright retained	Prohibited for commercial use	Prohibited for commercial use	Prohibited
Fireball	Prohibited without prior permission	Allowable for personal, noncommercial use with copyright retained and no modifications	Not specified	Prohibited without prior permission	Not specified
Lyrica	Prohibited without prior permission	Allowable for noncommercial individual references with copyright retained	Allowable for noncommercial individual references with copyright retained	Prohibited without prior permission	Not specified
Invega Sustenna	Prohibited for commercial use without prior permission	Allowable for personal, noncommercial purposes with copyrights retained	Prohibited for commercial use without prior permission	Allowable for personal, noncommercial purposes with copyrights retained	Prohibited for commercial use without prior permission
McDonalds	Allowable for personal, noncommercial purposes	Not specified	Prohibited for commercial use	Prohibited for commercial use	Prohibited
Starbucks	Not specified	Not specified	Not specified	Prohibited	Not specified
Subway	Prohibited for commercial use	Not specified	Prohibited without prior permission	Prohibited without prior permission	Prohibited without prior permission
Remington Outdoor	Allowable occasionally with an insubstantial portion of the content for noncommercial purposes with copyrights retained and including "Used with permission from Remington"	Prohibited	Prohibited	Allowable occasionally with an insubstantial portion of the content for noncommercial purposes with copyrights retained and including "Used with permission from Remington"	Not specified
Sturm Ruger	Prohibited without prior permission	Allowable for personal and authorized commercial use	Allowable for personal and authorized commercial use	Prohibited without prior permission	Not specified
Smith and Wesson	Not specified	Allowable for personal, noncommercial, and informational use	Prohibited without prior permission	Prohibited	Not specified

Discussion

Principal Findings

Our exploration of TOS has revealed several important conclusions and raised some significant insights that we will discuss in the context of recent litigation: (1) research on web-based spaces is complicated by the existence of TOS in that they restrict activities necessary for research; (2) commercial entities are creating spaces on the web and some use TOS to try to restrict access to those spaces; and (3) research on private web-based spaces is ethically justifiable, regardless of whether the activities necessary to conduct this research are allowed under TOS agreements, but this research is legally questionable, so how should researchers proceed? Companies already have the financial power to aggressively market their products both on and off the web; in addition, they also have the power to define what is and is not allowed regarding the use of their website material via TOS [63,84]. This power apparently allows companies to restrict access to websites and restrict specific activities one can do with the website material. Some of the restricted activities are necessary to conduct research, and the existence of TOS calls into question the legality of conducting such research. Researchers, then, may be left feeling unsure of how to conduct necessary monitoring of web-based commercial spaces without risking legal action [61].

TOS are complicated and cloud the legality of research on consumer product websites. It is important for regulatory agencies to have data on websites to make informed marketing regulations. The FDA, for instance, calls on members of the public, including researchers, to report marketing violations in Section 3.1.4 of the *Tobacco Control Act Enforcement Manual* [46]; however, performing basic tasks to document content and marketing strategies on the web is made difficult or impossible if researchers are bound by TOS such as those outlined. It is notable that these TOS potentially restrict many of the activities needed to conduct a basic content analysis (Table 4), a research method that provides details on the content and marketing strategies employed on websites. For instance, researchers need to save and share website content for content coding, analysis, and potentially for later reporting. All activities that are necessary to conduct a content analysis (which we defined as displaying, downloading, copying, distributing, and translating) were only explicitly allowed by one website TOS. Such restrictions were also noted during an evaluation of TOS on social media websites [62]. Website content changes frequently, and not saving content, which typically requires downloading, would likely result in lost data, which would be untenable for effective surveillance or academic analytic processes. Translation is also sometimes necessary for international work assessing websites used in other countries, necessitating both translation and sharing content with others, activities often prohibited by TOS.

Most of the explored TOS also state that the company can restrict access at any time, sometimes for any reason. If a company chooses to do this in the midst of data collection, it could impose a significant barrier. None of the TOS in this sample provided any information regarding an appeals process

to contest restricted access. It is possible that some companies might intentionally restrict access if they think a user is accessing the website for research purposes that might reflect badly on the company, using their TOS-stated right to restrict access at any time and/or for any reason as a rationale.

Researchers could try to create a protocol that would follow the TOS for all the commercial websites they were interested in studying. However, attempting this could be difficult, as TOS can vary considerably across websites and include legal jargon [85,86]. Researchers could limit their sample based on websites that allow the required research activities; however, this would likely result in an unrepresentative sample and could exclude websites where TOS tends to prohibit more activities, such as tobacco websites. It is possible that companies employing more problematic marketing tactics might have more restrictive TOS, and those are the companies that are most important to monitor.

In addition, one of the most consistent finding across product type is terms stating that website content can only be used for personal, noncommercial use. It is unclear if research fits in this category. It seems fairly clear that it is not *personal*, as the purpose of research is to disseminate findings to the scientific community and the public. At the same time, it is also clear that public health research is not a commercial pursuit: profit is not the goal of the endeavor. None of the TOS in our small sample and only one in the larger sample of social media sample examined by Fiesler et al [62] explicitly address the use of websites for research purposes; therefore, it remains unclear if research activities are prohibited by corporations or not. Fiesler et al [62] conclude that TOS on consumer websites, such as TOS on social media websites, are “ambiguous and largely devoid of context,” making them difficult to understand and abide by. Arguments using the First Amendment’s protection of free speech have been raised recently in the Supreme Court, and although the court did not consider those arguments, it is possible that they could be called upon if needed [87].

We must then attempt to untangle what companies claim is binding in their TOS, compared with what the US courts have upheld as legally binding during litigation to better understand if researchers are truly bound by the limitations imposed by TOS. The Computer Fraud and Abuse Act (CFAA) is a federal law that prohibits accessing a computer without authorization or in a manner that exceeds authorization, which can be interpreted as a federal prohibition on TOS violations [88]. The recent memorandum opinion published by the US District Court for the District of Columbia in the case of *Sandvig v. Barr* [87] stated that merely violating TOS on public websites does not constitute a breach of the CFAA for exceeding authorized access to a computer and, therefore, cannot trigger federal criminal charges. In this case, researchers and journalists asked the court for clarity in a pre-enforcement challenge if the work they wanted to conduct (analyzing if algorithms on hiring websites discriminate based on race, gender, age, or other attributes by creating fictitious user profiles) would violate the CFAA and trigger criminal charges. The court stated that in cases where any user can access a website, even if users are required to create a username and password for access (ie, the website is public), violating the TOS is not a CFAA violation. Although this is certainly good news for researchers who want to conduct

research on public websites, the court clarified that TOS violations may still trigger federal and state civil charges. Such violations would amount to the web-based equivalent of trespassing; however, as long as researchers are not inflicting damage by slowing down website operations, preventing other user access, or tampering with content, it is unclear what damages companies could request compensation for.

Variability in the jurisdictions selected for governing the TOS and litigation may impact what state civil charges companies could bring for researcher trespass. Companies largely control the state where litigation will occur, and different states may have different laws governing what constitutes trespass and the consequences for trespassing. This introduces more uncertainty in terms of what research activities could result in civil charges.

Although the memorandum in *Sandvig v. Barr* offers researchers conducting research on public websites reassurances, the issue of research on private websites remains of questionable legality. In light of recent litigation, it is also possible that companies will restrict access to their websites and create private spaces where research activities continue to be more limited. Tobacco companies already restrict access to their websites and even require authentication of provided information. A researcher may not be able to gain access to view the selected tobacco website content without providing false information to register (eg, falsely identify themselves as a smoker). Doing so would serve as a breach of TOS because of the requirement that registrants be tobacco users and provide only true information. Violating TOS by conducting research activities that require downloading, sharing, and so on, on a private website may also still constitute a violation of the CFAA, which can trigger federal criminal charges. Tobacco websites were the only websites that are considered private in this sample, and these websites prohibited or severely restricted all the activities necessary to conduct a content analysis.

If researchers are convinced of the public health need to surveil private websites but are not able to do so while adhering to TOS, there are potentially incompatible legal and ethical issues to weigh. The ethical issues raised by such surveillance research are limited to the extent that surveillance activities do not seek to analyze interaction between users but rather seek to document the content of the website as it is designed by companies. In other words, it is a commercial entity rather than an individual who is being surveilled. From an ethical perspective, it is arguable that corporate actions do not warrant the same protection as human subjects, with the result that corporations may not be able to claim the right to autonomy from research participation. There is precedence for treatment of commercial organizations differently from individuals in research; company names are often used in academic publication, and there is no existing standard stating that companies should not have identifiable information disclosed.

The legal issues underlying research on websites vary in magnitude depending on whether the website is public, where anyone can create log-in credentials or access website content without a log-in, or private, where websites require authentication of provided information and apply constraints regarding who is allowed to create log-in credentials. The legal

issue of research on public websites appears to be more limited. The biggest threat, violation of the CFAA, has been largely removed, and civil charges at the state or federal level seem unlikely when no damage is done to the websites of interest. Research on public websites should be encouraged and expanded to provide the public health community with a better understanding of e-marketing tactics and opportunities to inform marketing regulations that would better protect public health. This is especially important in the present moment when research requiring face-to-face interaction is limited by the ongoing pandemic. The legal issue of research on private websites presents a greater challenge. Even if a court was to eventually rule that violating TOS on private websites for public health research is not a violation of the CFAA, being sued and facing the litigation that follows is time consuming and has the potential to hurt the credibility and reputation of the researcher. Such damage might reduce the likelihood of promotion or achieving tenure if it is costly for the institution to defend the researcher. This is particularly problematic for private tobacco websites, as the tobacco industry has a long history of targeted and aggressive marketing of a product that is intrinsically harmful to users. Although account requirements may ostensibly be to responsibly keep out youth and nonsmokers, it also limits the access of the researchers and makes their access potentially illegal. Further, there is nothing stopping other companies that sell harmful products from putting up similar restrictions.

This study has also revealed the involvement of research institutions and universities as key stakeholders in decisions regarding research involving TOS violations. The expectations for researchers need to be clearly defined and understood in the various relevant offices of the university such that important research can be undertaken in such a way that the institution is comfortable with and can (and will) stand behind the researchers in the case of industry action. Currently, these issues are beyond the scope of what institutional review boards perceive as their purview, leaving researchers with few resources for guidance on questions of both ethics and legal issues [89].

We would conclude that violating TOS to conduct public health research on product websites is not ethically questionable; rather, given the public health significance of e-marketing, we may be ethically bound to conduct such research, regardless of whether it occurs on public or private websites. This conclusion has similarly been reached by the Association for Computing Machinery's Committee on Professional Ethics in their Code of Ethics and Professional Conduct, which states that TOS and other internet regulations should be followed unless there is a "compelling ethical justification to do otherwise" [90]. The code goes on to state that those who violate TOS for ethical or any other reasons "must accept responsibility for that action and for its consequences" [90]. How, then, should researchers proceed with research on private product websites in a way that minimizes or eliminates legal risks? An important question is whether researchers are in any way precluded from TOS restrictions. Beyond this general question, researchers could contact companies and request permission to study their website. Although this option might grant researchers access, it would also put the company on notice that research is being conducted, and there is no great incentive for companies to agree to

surveillance. It is critical that the public health community establish standards for such researchers to enable the continuation of this important work in ways that the researchers and institutions involved are protected.

Limitations

This study explored a small and purposefully selected sample of commercial product website TOS. It is possible that we missed variability in TOS that might be present on other types of websites. We also limited our sample to US companies, and TOS for companies within the United States might be different from the website TOS for companies in other countries, and caution should be used when attempting to generalize these results. The TOS observed during this study were downloaded and analyzed in July 2018. As of July 2020, 7 websites have updated their TOS. A brief review of updated TOS shows that very little has changed in terms of allowable activities with website material. The only exception to this was Jim Beam. Jim Beam added a clause that “You may print or download one copy of a reasonable number of pages of this Website for your own personal, noncommercial use and not for further reproduction, publication, or distribution” and some language allowing app download. We also employed confirmatory coding, rather than blind double-coding, which may have biased the second coder. Given that we were unable to access the content for tobacco websites, we were unable to conduct a content analysis to determine if our hypothesis that websites with more problematic content would be those with stricter TOS was correct.

In addition, none of the coders were lawyers, although lawyers were consulted to ensure that terms were coded appropriately and their significance was understood. As noted by others who have studied TOS and other similar contracts, terms can approach incomprehensibility, even for legal experts [85,86,91]. We discussed our findings and the legal implications of violating TOS for research with a lawyer and 2 law students at the

Cyberlaw Clinic at the Harvard Law School, who validated that the legal landscape is continuously changing and it is currently unclear if creating false accounts on private websites (in the context of gaining access to a tobacco website) would be considered a violation of the CFAA. The US government has never charged a researcher for violating TOS in the course of their research, and the recent Sandvig decision certainly reduces the risk of this for research on public websites; however, the risk of violating the CFAA while researching private websites such as tobacco websites remains unclear.

This study was limited to TOS contracts and did not include the evaluation of privacy policies. A privacy policy is a “legal document that discloses some or all of the ways a party gathers, uses, discloses and manages a customer's data” [92]. As this study did not assess privacy policies, it cannot state what kind of surveillance researchers have to agree to when they are attempting to surveil consumer product websites. This is an important area of future exploration and would add to the existing work on privacy policies by Bagley and Brown [52] and Obar and Oeldorf-Hirsch [56].

Conclusions

E-marketing on brand websites is an important area for public health surveillance to monitor; however, TOS complicate this endeavor by restricting access and prohibiting activities needed to conduct research. Recent court opinions have reduced the risk of federal criminal charges for violating TOS on public websites, but this risk remains unclear for private websites. Researchers already engaged in research on private websites are putting themselves in danger of being sued, and their affiliated institutions may or may not support them in court. It is critical that the public health community establishes standards for conducting research on e-marketing that supports this important public health issue.

Acknowledgments

This work was supported by funding from Bloomberg Philanthropies' Bloomberg Initiative to Reduce Tobacco Use and the Practical Ethics Grant from the Johns Hopkins Berman Center for Bioethics. CW was supported by T32 CA009314 during publication development. Christopher Bavitz, Juris Doctor; William Walker; and Leo Ding from the Cyberlaw Clinic at the Harvard School of Law assisted with legal research and reviewed this manuscript to ensure that the legal context the authors provided was accurate.

Conflicts of Interest

MD holds equity in Sickweather Inc and has received consulting fees from Bloomberg LP and Good Analytics Inc. These organizations did not have any role in the study design, data collection and analysis, decision to publish, or preparation of the article. MBM serves as a paid expert witness in litigation sponsored by the Public Health Advocacy Institute against RJ Reynolds. This arrangement has been reviewed and approved by the Johns Hopkins University in accordance with its conflict of interest policies.

References

1. Majnoni DB. Épidémies industrielles. Commentaire. 1995. URL: <https://www.commentaire.fr/boutique/achat-d-articles/epidemies-industrielles-4517> [accessed 2018-09-25]
2. GBD 2017 Risk Factor Collaborators. Global, regional, and national comparative risk assessment of 84 behavioural, environmental and occupational, and metabolic risks or clusters of risks for 195 countries and territories, 1990-2017: a

- systematic analysis for the Global Burden of Disease Study 2017. *Lancet* 2018 Nov 10;392(10159):1923-1994 [FREE Full text] [doi: [10.1016/S0140-6736\(18\)32225-6](https://doi.org/10.1016/S0140-6736(18)32225-6)] [Medline: [30496105](https://pubmed.ncbi.nlm.nih.gov/30496105/)]
3. FastStats - Injuries Internet. Centers for Disease Control and Prevention National Center for Health Statistics. 2017. URL: <https://www.cdc.gov/nchs/fastats/injury.htm> [accessed 2018-09-25]
 4. WONDER Underlying Cause of Death, 1999-2018. Centers for Disease Control and Prevention. 2018. URL: <http://wonder.cdc.gov/ucd-icd10.html> [accessed 2020-04-06]
 5. Jahiel RI. Corporation-induced diseases, upstream epidemiologic surveillance, and urban health. *J Urban Health* 2008 Jul;85(4):517-531 [FREE Full text] [doi: [10.1007/s11524-008-9283-x](https://doi.org/10.1007/s11524-008-9283-x)] [Medline: [18437580](https://pubmed.ncbi.nlm.nih.gov/18437580/)]
 6. Federal Trade Commission Cigarette Report for 2016. Federal Trade Commission. 2018. URL: https://www.ftc.gov/system/files/documents/reports/federal-trade-commission-cigarette-report-2016-federal-trade-commission-smokeless-tobacco-report-ftc-cigarette-report-for-2016_0.pdf [accessed 2018-06-04]
 7. Self-Regulation in the Alcohol Industry: Report of the Federal Trade Commission. Federal Trade Commission. 2014. URL: <https://www.ftc.gov/system/files/documents/reports/self-regulation-alcohol-industry-report-federal-trade-commission/140320alcoholreport.pdf> [accessed 2018-10-29]
 8. Ventola CL. Direct-to-consumer pharmaceutical advertising: therapeutic or toxic? *P T* 2011 Oct;36(10):669-684 [FREE Full text] [Medline: [22346300](https://pubmed.ncbi.nlm.nih.gov/22346300/)]
 9. Harris J, Schwartz M, Munsell S. Fast Food Facts 2013: Measuring Progress in Nutrition and Marketing to Children and Teens. *Yale Rudd Cent Food Policy Obes*. 2013. URL: <https://www.rwjf.org/content/dam/farm/reports/reports/2013/rwjf408549> [accessed 2018-10-28]
 10. Lovato C, Watts A, Stead LF. Impact of tobacco advertising and promotion on increasing adolescent smoking behaviours. *Cochrane Database Syst Rev* 2011 Oct 5(10):CD003439 [FREE Full text] [doi: [10.1002/14651858.CD003439.pub2](https://doi.org/10.1002/14651858.CD003439.pub2)] [Medline: [21975739](https://pubmed.ncbi.nlm.nih.gov/21975739/)]
 11. de Bruijn A, Tanghe J, de Leeuw R, Engels R, Anderson P, Beccaria F, et al. European longitudinal study on the relationship between adolescents' alcohol marketing exposure and alcohol use. *Addiction* 2016 Oct;111(10):1774-1783. [doi: [10.1111/add.13455](https://doi.org/10.1111/add.13455)] [Medline: [27486952](https://pubmed.ncbi.nlm.nih.gov/27486952/)]
 12. Gordon R, Harris F, Marie Mackintosh A, Moodie C. Assessing the cumulative impact of alcohol marketing on young people's drinking: cross-sectional data findings. *Addict Res Theory* 2010 Sep 7;19(1):66-75. [doi: [10.3109/16066351003597142](https://doi.org/10.3109/16066351003597142)]
 13. Kelly B, King MPsy L, Chapman Mnd K, Boyland E, Bauman AE, Baur LA. A hierarchy of unhealthy food promotion effects: identifying methodological approaches and knowledge gaps. *Am J Public Health* 2015 Apr;105(4):e86-e95. [doi: [10.2105/AJPH.2014.302476](https://doi.org/10.2105/AJPH.2014.302476)] [Medline: [25713968](https://pubmed.ncbi.nlm.nih.gov/25713968/)]
 14. Andreyeva T, Kelly I, Harris J. Exposure to food advertising on television: associations with children's fast food and soft drink consumption and obesity. *Econ Hum Biol* 2011 Jul;9(3):221-233. [doi: [10.1016/j.ehb.2011.02.004](https://doi.org/10.1016/j.ehb.2011.02.004)] [Medline: [21439918](https://pubmed.ncbi.nlm.nih.gov/21439918/)]
 15. Dixon H, Scully M, Niven P, Kelly B, Chapman K, Donovan R, et al. Effects of nutrient content claims, sports celebrity endorsements and premium offers on pre-adolescent children's food preferences: experimental research. *Pediatr Obes* 2014 Apr;9(2):e47-e57. [doi: [10.1111/j.2047-6310.2013.00169.x](https://doi.org/10.1111/j.2047-6310.2013.00169.x)] [Medline: [23630014](https://pubmed.ncbi.nlm.nih.gov/23630014/)]
 16. Wintemute G. Where the guns come from: the gun industry and gun commerce. *Future Children* 2002;12(2):54. [doi: [10.2307/1602738](https://doi.org/10.2307/1602738)]
 17. Avery RJ, Eisenberg MD, Simon KI. The impact of direct-to-consumer television and magazine advertising on antidepressant use. *J Health Econ* 2012 Sep;31(5):705-718. [doi: [10.1016/j.jhealeco.2012.05.002](https://doi.org/10.1016/j.jhealeco.2012.05.002)] [Medline: [22835472](https://pubmed.ncbi.nlm.nih.gov/22835472/)]
 18. Daubresse M, Hutfless S, Kim Y, Kornfield R, Qato DM, Huang J, et al. Effect of direct-to-consumer advertising on asthma medication sales and healthcare use. *Am J Respir Crit Care Med* 2015 Jul 1;192(1):40-46 [FREE Full text] [doi: [10.1164/rccm.201409-1585OC](https://doi.org/10.1164/rccm.201409-1585OC)] [Medline: [25879303](https://pubmed.ncbi.nlm.nih.gov/25879303/)]
 19. Layton JB, Kim Y, Alexander GC, Emery SL. Association between direct-to-consumer advertising and testosterone testing and initiation in the united states, 2009-2013. *J Am Med Assoc* 2017 Mar 21;317(11):1159-1166 [FREE Full text] [doi: [10.1001/jama.2016.21041](https://doi.org/10.1001/jama.2016.21041)] [Medline: [28324090](https://pubmed.ncbi.nlm.nih.gov/28324090/)]
 20. Cairns G, Angus K, Hastings G, Caraher M. Systematic reviews of the evidence on the nature, extent and effects of food marketing to children. A retrospective summary. *Appetite* 2013 Mar;62:209-215. [doi: [10.1016/j.appet.2012.04.017](https://doi.org/10.1016/j.appet.2012.04.017)] [Medline: [22561190](https://pubmed.ncbi.nlm.nih.gov/22561190/)]
 21. Jernigan D, Noel J, Landon J, Thornton N, Lobstein T. Alcohol marketing and youth alcohol consumption: a systematic review of longitudinal studies published since 2008. *Addiction* 2017 Jan;112(Suppl 1):7-20. [doi: [10.1111/add.13591](https://doi.org/10.1111/add.13591)] [Medline: [27565582](https://pubmed.ncbi.nlm.nih.gov/27565582/)]
 22. Moore D, Lee S. How advertising influences consumption impulses: the role of visualization, anticipated emotions, taste anticipation, and hedonic rationalization. *J Advert* 2012;41(3):107-120. [doi: [10.2753/JOA0091-3367410307](https://doi.org/10.2753/JOA0091-3367410307)]
 23. DiFranza JR, Wellman RJ, Sargent JD, Weitzman M, Hipple BJ, Winickoff JP, Tobacco Consortium, Center for Child Health Research of the American Academy of Pediatrics. Tobacco promotion and the initiation of tobacco use: assessing the evidence for causality. *Pediatrics* 2006 Jun;117(6):e1237-e1248. [doi: [10.1542/peds.2005-1817](https://doi.org/10.1542/peds.2005-1817)] [Medline: [16740823](https://pubmed.ncbi.nlm.nih.gov/16740823/)]

24. Wellman RJ, Sugarman DB, DiFranza JR, Winickoff JP. The extent to which tobacco marketing and tobacco use in films contribute to children's use of tobacco: a meta-analysis. *Arch Pediatr Adolesc Med* 2006 Dec;160(12):1285-1296. [doi: [10.1001/archpedi.160.12.1285](https://doi.org/10.1001/archpedi.160.12.1285)] [Medline: [17146027](https://pubmed.ncbi.nlm.nih.gov/17146027/)]
25. Pucci LG, Siegel M. Exposure to brand-specific cigarette advertising in magazines and its impact on youth smoking. *Prev Med* 1999 Nov;29(5):313-320. [doi: [10.1006/pmed.1999.0554](https://doi.org/10.1006/pmed.1999.0554)] [Medline: [10564621](https://pubmed.ncbi.nlm.nih.gov/10564621/)]
26. Gilpin EA, White MM, Messer K, Pierce JP. Receptivity to tobacco advertising and promotions among young adolescents as a predictor of established smoking in young adulthood. *Am J Public Health* 2007 Aug;97(8):1489-1495. [doi: [10.2105/AJPH.2005.070359](https://doi.org/10.2105/AJPH.2005.070359)] [Medline: [17600271](https://pubmed.ncbi.nlm.nih.gov/17600271/)]
27. Pierce JP, Choi WS, Gilpin EA, Farkas AJ, Berry CC. Tobacco industry promotion of cigarettes and adolescent smoking. *J Am Med Assoc* 1998 Feb 18;279(7):511-515. [doi: [10.1001/jama.279.7.511](https://doi.org/10.1001/jama.279.7.511)] [Medline: [9480360](https://pubmed.ncbi.nlm.nih.gov/9480360/)]
28. Pechmann C, Levine L, Loughlin S, Leslie F. Impulsive and self-conscious: adolescents' vulnerability to advertising and promotion. *J Public Policy Mark* 2018 Oct 18;24(2):202-221. [doi: [10.1509/jppm.2005.24.2.202](https://doi.org/10.1509/jppm.2005.24.2.202)]
29. Biener L, Siegel M. Tobacco marketing and adolescent smoking: more support for a causal inference. *Am J Public Health* 2000 Mar;90(3):407-411. [doi: [10.2105/ajph.90.3.407](https://doi.org/10.2105/ajph.90.3.407)] [Medline: [10705860](https://pubmed.ncbi.nlm.nih.gov/10705860/)]
30. Tickle JJ, Hull JG, Sargent JD, Dalton MA, Heatherton TF. A structural equation model of social influences and exposure to media smoking on adolescent smoking. *Basic Appl Soc Psych* 2010 Jun 7;28(2):117-129. [doi: [10.1207/s15324834basps2802_2](https://doi.org/10.1207/s15324834basps2802_2)]
31. The Role of the Media in Promoting and Reducing Tobacco Use. Tobacco Control Monograph No 19. Department of Health and Human Services, National Institutes of Health, National Cancer Institute. 2008. URL: https://cancercontrol.cancer.gov/brp/tcrb/monographs/19/m19_complete.pdf [accessed 2018-07-27]
32. Nakajima S. State of Online Advertising Worldwide. The Free Library. 2016. URL: <https://www.thefreelibrary.com/State+of+online+advertising+worldwide.-a0489758447> [accessed 2018-09-26]
33. Clement J. Worldwide Digital Population as of January. Statista. 2020. URL: <https://www-statista-com.proxy1.library.jhu.edu/statistics/617136/digital-population-worldwide/> [accessed 2020-05-03]
34. Cooke E, Hastings G, Wheeler C, Eadie D, Moskalewicz J, Dabrowska K. Marketing of alcohol to young people: a comparison of the UK and Poland. *Eur Addict Res* 2004;10(1):1-7. [doi: [10.1159/000073720](https://doi.org/10.1159/000073720)] [Medline: [14665799](https://pubmed.ncbi.nlm.nih.gov/14665799/)]
35. Cruz T. Monitoring the tobacco use epidemic IV. The vector: Tobacco industry data sources and recommendations for research and evaluation. *Prev Med* 2009 Jan;48(1 Suppl):S24-S34. [doi: [10.1016/j.ypmed.2008.10.002](https://doi.org/10.1016/j.ypmed.2008.10.002)] [Medline: [18976685](https://pubmed.ncbi.nlm.nih.gov/18976685/)]
36. Ilakkuvan V, Cantrell J, Vallone D. 'Action. Adventure. Special offers.': how Marlboro engages consumers on its website. *Tob Control* 2014 Sep;23(5):455-456. [doi: [10.1136/tobaccocontrol-2013-051115](https://doi.org/10.1136/tobaccocontrol-2013-051115)] [Medline: [23853251](https://pubmed.ncbi.nlm.nih.gov/23853251/)]
37. Astuti P, Assunta M, Freeman B. Raising generation 'A': a case study of millennial tobacco company marketing in Indonesia. *Tob Control* 2018 Jul;27(e1):e41-e49. [doi: [10.1136/tobaccocontrol-2017-054131](https://doi.org/10.1136/tobaccocontrol-2017-054131)] [Medline: [30042229](https://pubmed.ncbi.nlm.nih.gov/30042229/)]
38. Weiger CV, Smith K, Hong AY, Cohen JE. Cigarette packs with urls leading to tobacco company websites: content analysis. *J Med Internet Res* 2020 Jun 9;22(6):e15160 [FREE Full text] [doi: [10.2196/15160](https://doi.org/10.2196/15160)] [Medline: [32459649](https://pubmed.ncbi.nlm.nih.gov/32459649/)]
39. Trimble D, Welding K, Smith KC, Cohen J. Smoke and scan: a content analysis of qr code-directed websites found on cigarette packs in China. *Nicotine Tob Res* 2020 Oct 8;22(10):1912-1916. [doi: [10.1093/ntr/ntaa091](https://doi.org/10.1093/ntr/ntaa091)] [Medline: [32447384](https://pubmed.ncbi.nlm.nih.gov/32447384/)]
40. Hurwitz L, Montague H, Wartella E. Food marketing to children online: a content analysis of food company websites. *Health Commun* 2017 Mar;32(3):366-371. [doi: [10.1080/10410236.2016.1138386](https://doi.org/10.1080/10410236.2016.1138386)] [Medline: [27309792](https://pubmed.ncbi.nlm.nih.gov/27309792/)]
41. Moore E, Rideout V. The online marketing of food to children: is it just fun and games? *J Public Policy Mark* 2018 Oct 10;26(2):202-220. [doi: [10.1509/jppm.26.2.202](https://doi.org/10.1509/jppm.26.2.202)]
42. Feasby J, Brady J, Farrell A, Wong S, Mendelson R. Online marketing of food and beverages to children. *Can J Diet Pract Res* 2011 Jul;72(2):59. [doi: [10.3148/72.2.2011.59](https://doi.org/10.3148/72.2.2011.59)]
43. Jordan L, Kalin J, Dabrowski C. Characteristics of gun advertisements on social media: systematic search and content analysis of Twitter and YouTube posts. *J Med Internet Res* 2020 Mar 27;22(3):e15736 [FREE Full text] [doi: [10.2196/15736](https://doi.org/10.2196/15736)] [Medline: [32217496](https://pubmed.ncbi.nlm.nih.gov/32217496/)]
44. Ribisl KM. The potential of the internet as a medium to encourage and discourage youth tobacco use. *Tob Control* 2003 Jun;12(Suppl 1):i48-i59 [FREE Full text] [doi: [10.1136/tc.12.suppl_1.i48](https://doi.org/10.1136/tc.12.suppl_1.i48)] [Medline: [12773785](https://pubmed.ncbi.nlm.nih.gov/12773785/)]
45. Freeman B, Chapman S. Gone viral? Heard the buzz? A guide for public health practitioners and researchers on how Web 2.0 can subvert advertising restrictions and spread health information. *J Epidemiol Community Health* 2008 Sep;62(9):778-782. [doi: [10.1136/jech.2008.073759](https://doi.org/10.1136/jech.2008.073759)] [Medline: [18701726](https://pubmed.ncbi.nlm.nih.gov/18701726/)]
46. Enforcement Action Plan for Promotion and Advertising Restrictions Internet. Silver Spring. 2010. URL: <https://www.fda.gov/media/79017/download> [accessed 2020-07-13]
47. Gordon R. An audit of alcohol brand websites. *Drug Alcohol Rev* 2011 Nov;30(6):638-644. [doi: [10.1111/j.1465-3362.2010.00257.x](https://doi.org/10.1111/j.1465-3362.2010.00257.x)] [Medline: [21355900](https://pubmed.ncbi.nlm.nih.gov/21355900/)]
48. Hoffman B. Searching eyes: privacy, the state, and disease surveillance in America. *J Health Politics Policy Law* 2009 Dec 16;34(6):1079-1082. [doi: [10.1215/03616878-2009-036](https://doi.org/10.1215/03616878-2009-036)]
49. What is Terms and Conditions? Black's Law Dictionary. 2020. URL: <https://thelawdictionary.org/terms-and-conditions/> [accessed 2020-10-29]

50. Schnabel v Trilegiant Corp. Justia Cases. 2012 Sep 07. URL: <https://cases.justia.com/federal/appellate-courts/ca2/11-1311/11-1311-2012-09-07.pdf?ts=1410918474> [accessed 2018-10-29]
51. Register.com Inc Plaintiff-appellee, v Verio, Inc Defendant-appellant, 356 F.3d 393 (2d Cir 2004). Justia US Law. 2004. URL: <https://law.justia.com/cases/federal/appellate-courts/F3/356/393/539823/> [accessed 2018-10-29]
52. Bagley A, Brown J. Limited consumer privacy protections against the layers of big data. *Santa Clara High Technol Law J* 2015;31(3):483-526 [FREE Full text]
53. Casetext. 2012 Dec 11. URL: <https://casetext.com/case/hancock-v-am-tel-tel-co> [accessed 2020-07-13]
54. Casetext. 2014 Aug 18. URL: <https://casetext.com/case/nguyen-v-barnes-noble-inc> [accessed 2020-07-13]
55. Specht v Netscape Communications Corp 150 F Supp 2d 585. Justia US Law. 2001 Jul 5. URL: <https://law.justia.com/cases/federal/district-courts/FSupp2/150/585/2468233/> [accessed 2020-07-13]
56. Obar JA, Oeldorf-Hirsch A. The biggest lie on the internet: ignoring the privacy policies and terms of service policies of social networking services. *Inform Commun Soc* 2018 Jul 3;23(1):128-147. [doi: [10.1080/1369118x.2018.1486870](https://doi.org/10.1080/1369118x.2018.1486870)]
57. Steinfeld N. 'I agree to the terms and conditions': (how) do users read privacy policies online? An eye-tracking experiment. *Comput Human Behav* 2016 Feb;55:992-1000. [doi: [10.1016/j.chb.2015.09.038](https://doi.org/10.1016/j.chb.2015.09.038)]
58. Susan G. Nobody reads your privacy policy or online contract: lessons learned and questions raised by the FTC's action against Sears. *Nw J Tech Intell* 2009;8(1):1 [FREE Full text]
59. Frischmann B, Selinger E. Engineering humans with contracts. In: *Re-Engineering Humanity*. Cambridge, UK: Cambridge University Press; 2018:60-80.
60. Radin M. Boilerplate, consumers' rights, and the rule of law. In: *Boilerplate: The Fine Print, Vanishing Rights, and the Rule of Law*. Princeton, New Jersey: Princeton University Press; 2012:14-47.
61. Weller K, Kinder-Kurlanda K. To share or not to share?: ethical challenges in sharing social media-based research data. In: *Internet Research Ethics for the Social Age: New Challenges, Cases, and Contexts*. New York, USA: Peter Lang; 2017:115-129.
62. Fiesler C, Beard N, Keegan B. No Robots, Spiders, or Scrapers: Legal and Ethical Regulation of Data Collection Methods in Social Media Terms of Service. Association for the Advancement of Artificial Intelligence. URL: https://cmci.colorado.edu/~cafi5706/ICWSM2020_datascraping.pdf [accessed 2020-04-21]
63. Vaccaro K, Hamilton K, Karahalios K, Langbort C, Sandvig C. Agree or Cancel? Research and Terms of Service Compliance. In: *Ethics Work Ethics Stud Sociotechnical Syst a Big Data World*. 2015 Presented at: AMC'15; October 17-21, 2015; Chicago, USA URL: https://www.researchgate.net/publication/335327933_Agree_or_Cancel_Research_and_Terms_of_Service_Compliance
64. Vitak J, Shilton K, Ashktorab Z. Beyond the Belmont Principles: Ethical Challenges, Practices, and Beliefs in the Online Data Research Community. In: *Association for Computing Machinery Digital Library*. 2016 Presented at: ACM'16; February 2-6, 2016; Vancouver, BC p. 953. [doi: [10.1145/2818048.2820078](https://doi.org/10.1145/2818048.2820078)]
65. Siegel A, Grosso A, Rasch M, Jarvis R. Brief for Amicus Curiae United States Technology Policy Committee of the ACM in Support of Neither Party Internet. The Supreme Court of the United States. 2020. URL: https://www.supremecourt.gov/DocketPDF/19/19-783/147196/20200708104631325_Amicus%20Brief.pdf [accessed 2020-07-13]
66. The Statistics Portal. Statista. 2018. URL: <https://www-statista-com.ezp.welch.jhmi.edu/> [accessed 2018-07-18]
67. Kang H, An S. How direct-to-consumer drug websites convey disease information: analysis of stigma-reducing components. *J Health Commun* 2013;18(12):1477-1491. [doi: [10.1080/10810730.2013.798378](https://doi.org/10.1080/10810730.2013.798378)] [Medline: [24015752](https://pubmed.ncbi.nlm.nih.gov/24015752/)]
68. Abel GA, Penson RT, Joffe S, Schapira L, Chabner BA, Lynch TJ. Direct-to-consumer advertising in oncology. *Oncologist* 2006 Feb;11(2):217-226 [FREE Full text] [doi: [10.1634/theoncologist.11-2-217](https://doi.org/10.1634/theoncologist.11-2-217)] [Medline: [16476842](https://pubmed.ncbi.nlm.nih.gov/16476842/)]
69. Antidepressant Use Among Adults: United States, 2015-2018. Centers for Disease Control and Prevention. URL: [https://www.cdc.gov/nchs/products/databriefs/db377.htm#:~:text=During%202015%E2%80%932018,2%25%20of%20Americans%20aged%2018%20and,over%20\(24.3%25\)%20took%20antidepressants](https://www.cdc.gov/nchs/products/databriefs/db377.htm#:~:text=During%202015%E2%80%932018,2%25%20of%20Americans%20aged%2018%20and,over%20(24.3%25)%20took%20antidepressants) [accessed 2020-11-19]
70. Terms and Conditions of Use. New Port Pleasures. 2017. URL: <https://www.newport-pleasure.com/FooterLinks/TermsOfUse> [accessed 2018-07-19] [WebCite Cache ID 711ocrE9X]
71. Terms and Conditions Internet. Budlight. 2018. URL: <https://www.budlight.com/en/terms-conditions.html> [accessed 2018-07-19] [WebCite Cache ID 711pURwtg]
72. Miller Coors Terms and Conditions of Use. Miller Coors. 2018. URL: <https://www.millercoors.com/legal/terms> [accessed 2018-07-19] [WebCite Cache ID 711pMxRP8]
73. Brown-Forman Terms of Use. Brown-Forman. 2018. URL: <https://legal.brown-forman.com/terms-of-use/english> [accessed 2018-07-19] [WebCite Cache ID 711prriBa]
74. Terms of Use. Sazerac Company Inc. 2017. URL: <http://www.sazerac.com/sazeractermsfuse.html> [accessed 2018-07-19] [WebCite Cache ID 711qMx1do]
75. Terms of Use. Jim Beam Brands Co. 2018. URL: <http://www.jimbeam.com/en-us/terms> [accessed 2018-07-26] [WebCite Cache ID 71CXRN3s]
76. Web Site Terms of Use. Remington Arms Company LLC. 2018. URL: <https://www.remington.com/terms-use> [accessed 2018-07-19] [WebCite Cache ID 711r0DH9l]

77. American Outdoor Brands Corporation Website Privacy Notice and Policy. American Outdoor Brands Corporation. 2017 Apr. URL: <https://www.webcitation.org/711rDsxHR> [accessed 2018-07-19] [WebCite Cache ID 711rDsxHR]
78. Terms of Use. Sturm Ruger & Company Inc. 2018. URL: <http://www.webcitation.org/711rSgSIT> [accessed 2018-07-19] [WebCite Cache ID 711rSgSIT]
79. Terms of Use. Pfizer Inc. 2018. URL: <https://www.pfizer.com/general/terms> [accessed 2018-07-19] [WebCite Cache ID 711rfQ5vA]
80. Legal Terms of Use. Janssen Pharmaceutiacs Inc. 2017. URL: <https://www.invegasustenna.com/legal-notice> [accessed 2018-07-19] [WebCite Cache ID 711rpRzHB]
81. Terms and Conditions for McDonald's Online Services (USA). McDonald's. 2018. URL: <https://www.mcdonalds.com/us/en-us/terms-and-conditions.html> [accessed 2018-07-19] [WebCite Cache ID 711s5w4IF]
82. Terms of Use. Starbucks Corporation. 2018. URL: <https://www.starbucks.com/about-us/company-information/online-policies/terms-of-use> [accessed 2018-07-19] [WebCite Cache ID 711sHVLp6]
83. Web Site Terms of Use. Subway. 2018. URL: <https://www.subway.com/en-US/Legal/TermsOfUse> [accessed 2018-11-15] [WebCite Cache ID 73xCvmLvn]
84. Hoffmann A, Jones A. Recasting justice for internet and online industry research ethics. In: Internet Research Ethics for the Social Age: New Cases and Challenges. New York, USA: Peter Lang; 2016:3-19.
85. Fiesler C, Lampe C, Bruckman A. Reality and Perception of Copyright Terms of Service for Online Content Creation. In: 19th American Computing Machinery Conference. 2016 Presented at: ACM'16; October 2-4, 2016; Washington, DC. [doi: [10.1145/2818048.2819931](https://doi.org/10.1145/2818048.2819931)]
86. Reidenberg J, Breaux T, Cranor L, French B, Grannis A, Graves J, et al. Disagreeable privacy policies: mismatches between meaning and users understanding. SSRN J 2014. [doi: [10.2139/ssrn.2418297](https://doi.org/10.2139/ssrn.2418297)]
87. Sandvig v Barr. ACLU. 2020. URL: <https://www.aclu.org/sandvig-v-barr-memorandum-opinion> [accessed 2020-05-12]
88. Hughes W. Computer Fraud and Abuse Act of 1986. United States Congress. 1986. URL: <https://www.congress.gov/bills/99th-congress/house-bill/4718> [accessed 2020-07-14]
89. Vitak J, Proferes N, Shilton K, Ashktorab Z. Ethics regulation in social computing research: examining the role of institutional review boards. J Empir Res Hum Res Ethics 2017 Dec;12(5):372-382. [doi: [10.1177/1556264617725200](https://doi.org/10.1177/1556264617725200)] [Medline: [28831844](https://pubmed.ncbi.nlm.nih.gov/28831844/)]
90. Association for Computing Machinery's Code of Ethics and Professional Conduct. Association for Computing Machinery's Committee on Professional Ethics. 2018. URL: <https://ethics.acm.org/> [accessed 2020-04-21]
91. Luger E, Moran S, Rodden T. Consent for All: Revealing the Hidden Complexity of Terms and Conditions. In: SIGCHI Conference on Human Factors in Computing Systems. 2013 Presented at: CHI'13; April 27, 2013; Paris, France. [doi: [10.1145/2470654.2481371](https://doi.org/10.1145/2470654.2481371)]
92. Privacy Policy Law and Legal Definition. US Legal. 2020. URL: <https://definitions.uslegal.com/p/privacy-policy/> [accessed 2020-10-05]

Abbreviations

CFAA: Computer Fraud and Abuse Act

FDA: Food and Drug Administration

TOS: terms of service

Edited by G Eysenbach; submitted 19.08.20; peer-reviewed by L Jordan, A Phillips; comments to author 01.10.20; revised version received 13.10.20; accepted 28.10.20; published 02.12.20.

Please cite as:

Weiger C, Smith KC, Cohen JE, Dredze M, Moran MB

How Internet Contracts Impact Research: Content Analysis of Terms of Service on Consumer Product Websites

JMIR Public Health Surveill 2020;6(4):e23579

URL: <http://publichealth.jmir.org/2020/4/e23579/>

doi: [10.2196/23579](https://doi.org/10.2196/23579)

PMID: [33263555](https://pubmed.ncbi.nlm.nih.gov/33263555/)

©Caitlin Weiger, Katherine C Smith, Joanna E Cohen, Mark Dredze, Meghan Bridgid Moran. Originally published in JMIR Public Health and Surveillance (<http://publichealth.jmir.org>), 02.12.2020. This is an open-access article distributed under the terms of the Creative Commons Attribution License (<https://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in JMIR Public Health and

Surveillance, is properly cited. The complete bibliographic information, a link to the original publication on <http://publichealth.jmir.org>, as well as this copyright and license information must be included.

Original Paper

E-Cigarette Advocates on Twitter: Content Analysis of Vaping-Related Tweets

Kahlia McCausland¹, BSc; Bruce Maycock², PhD; Tama Leaver³, PhD; Katharina Wolf⁴, PhD; Becky Freeman⁵, PhD; Jonine Jancey¹, PhD

¹Collaboration for Evidence, Research and Impact in Public Health, School of Public Health, Curtin University, Bentley, Australia

²College of Medicine and Health, University of Exeter, Devon, United Kingdom

³School of Media, Creative Arts and Social Inquiry, Curtin University, Bentley, Australia

⁴School of Marketing, Curtin University, Bentley, Australia

⁵School of Public Health, University of Sydney, Sydney, Australia

Corresponding Author:

Kahlia McCausland, BSc

Collaboration for Evidence, Research and Impact in Public Health

School of Public Health

Curtin University

Kent Street

Bentley, 6102

Australia

Phone: 61 92667382

Email: kahlia.mccausland@curtin.edu.au

Abstract

Background: As the majority of Twitter content is publicly available, the platform has become a rich data source for public health surveillance, providing insights into emergent phenomena, such as vaping. Although there is a growing body of literature that has examined the content of vaping-related tweets, less is known about the people who generate and disseminate these messages and the role of e-cigarette advocates in the promotion of these devices.

Objective: This study aimed to identify key conversation trends and patterns over time, and discern the core voices, message frames, and sentiment surrounding e-cigarette discussions on Twitter.

Methods: A random sample of data were collected from Australian Twitter users who referenced at least one of 15 identified e-cigarette related keywords during 2012, 2014, 2016, or 2018. Data collection was facilitated by TrISMA (Tracking Infrastructure for Social Media Analysis) and analyzed by content analysis.

Results: A sample of 4432 vaping-related tweets posted and retweeted by Australian users was analyzed. Positive sentiment (3754/4432, 84.70%) dominated the discourse surrounding e-cigarettes, and vape retailers and manufacturers (1161/4432, 26.20%), the general public (1079/4432, 24.35%), and e-cigarette advocates (1038/4432, 23.42%) were the most prominent posters. Several tactics were used by e-cigarette advocates to communicate their beliefs, including attempts to frame e-cigarettes as safer than traditional cigarettes, imply that federal government agencies lack sufficient competence or evidence for the policies they endorse about vaping, and denounce as propaganda “gateway” claims of youth progressing from e-cigarettes to combustible tobacco. Some of the most common themes presented in tweets were advertising or promoting e-cigarette products (2040/4432, 46.03%), promoting e-cigarette use or intent to use (970/4432, 21.89%), and discussing the potential of e-cigarettes to be used as a smoking cessation aid or tobacco alternative (716/4432, 16.16%), as well as the perceived health and safety benefits and consequences of e-cigarette use (681/4432, 15.37%).

Conclusions: Australian Twitter content does not reflect the country’s current regulatory approach to e-cigarettes. Rather, the conversation on Twitter generally encourages e-cigarette use, promotes vaping as a socially acceptable practice, discredits scientific evidence of health risks, and rallies around the idea that e-cigarettes should largely be outside the bounds of health policy. The one-sided nature of the discussion is concerning, as is the lack of disclosure and transparency, especially among vaping enthusiasts who dominate the majority of e-cigarette discussions on Twitter, where it is unclear if comments are endorsed, sanctioned, or even supported by the industry.

KEYWORDS

electronic nicotine delivery systems; electronic cigarettes; e-cigarette; infodemiology; infoveillance; vaping; Twitter; social media; public health; content analysis

Introduction

The global e-cigarette market was worth US \$11.26 billion in 2018 [1] and is predicted to eclipse tobacco sales by 2023 [2]. Facilitating this growth is the increasing trend toward online retailing and social media consumption [3]. Social media has emerged as a popular forum for e-cigarette users (vapers) and prospective users to learn about and share their experiences with nicotine and vaping devices, for businesses to promote their products, and for e-cigarette advocates to debate regulatory regimes [4,5]. Digital media, including social media and social networking platforms, are increasingly preferred sources for health information and dissemination [6]. However, users may be inadvertently exposed to misinformation, disinformation, and unregulated advertising [7,8].

With its 330 million users [9], real-time content updates, and rapid information dissemination, Twitter contributes to e-cigarette marketing and information sharing [10]. As the majority of Twitter content is publicly available, the platform has become a rich data source for public health surveillance providing insights into emergent phenomena, such as vaping [11]. Recent investigations have shown that Twitter users are overwhelmingly exposed to positive messages about vaping, most notably marketing and promotion, and that public health messaging is particularly absent from communications [4]. Although there is a growing body of literature that has examined the content of vaping-related tweets [4,12], less is known about the people who generate and disseminate these messages, and the role of e-cigarette advocates in this promotion.

In Australia, the context of this study, the legal status of e-cigarettes is determined by existing and overlapping laws relating to poisons, therapeutic and consumer goods, and tobacco control [13]. Liquid nicotine is classified as a “Schedule 7-Dangerous Poison” under the Federal Poisons Standard [14], and, as such, the manufacture, sale, or supply of e-cigarettes containing nicotine without lawful authority (ie, prescription from a medical doctor) [15] is prohibited in all Australian states and territories [16]. However, nicotine-containing e-cigarettes are imported into Australia as there is no way to determine whether an e-cigarette contains nicotine without a laboratory analysis, which has implications for law enforcement [16,17]. E-cigarettes that do not contain nicotine can be sold in some Australian jurisdictions, provided manufacturers do not make therapeutic claims.

As of January 2019, there were approximately 2.56 million active monthly Australian Twitter users (64% male), which equates to approximately 12% of Australians over 13 years of age [18]. Given the popularity of Twitter [18], the ease of which information disseminates among its users, and the power of Twitter to traffic users to external webpages [19], insights into how the platform is used (and by whom) to promote and discuss

e-cigarettes are warranted. This study aimed to identify key conversation trends and patterns over time and discern the core voices, message frames, and sentiment surrounding e-cigarette discussions in an Australian context. Investigating these public conversations can contribute to understanding trends in knowledge, attitudes, and behaviors; identify marketing strategies; inform public health and public policy; and pave the way for interventions delivered via social media [20-23].

Methods

Data Collection

Twitter data were collected via TrISMA (Tracking Infrastructure for Social Media Analysis) [24], a contemporary technical and organizational infrastructure for the tracking of public communication by Australian users of social media. Central to the TrISMA Twitter infrastructure is the Australian Twitter Collection, which continuously gathers tweets from identified Australian accounts (ie, accounts set to an Australian location, geolocation, or time zone, or accounts with a description field referring to an Australian location or containing Australia-specific terms) and stores them in a database available to accredited TrISMA researchers. The TrISMA Twitter Collection is hosted on a cloud-based Google BigQuery database and is accessed through the data visualization tool Tableau. The Australian Twitter Collection filters for known signs of bots, such as accounts with numeric strings in the title, accounts with zero followers, and brand new accounts tweeting or retweeting identical content.

A list of popular e-cigarette-related terms was developed based on peer-reviewed literature [25-30], trending Twitter hashtags, and frequently co-occurring hashtags (ie, hashtags that appeared in the same caption as the root term), which resulted in the following 15 keywords: *cloudchasing*, *ecig* (includes e-cigarette/s), *e-cig* (includes e-cigarette/s), *electroniccig* (includes electroniccigarette/s), *electronic cigarette* (includes electronic cigarettes), *eliquid*, *e-liquid*, *e-juice*, *vape* (includes vaper and vapes), *vaping*, *vapecommunity*, *vapefam*, *vapelife*, *vapenation*, and *vapeporn*. E-cigarette product names were omitted from the search strategy so as not to bias the results to specific brands [22]. A preliminary search revealed there was minimal Twitter activity using these keywords before 2012. Two yearly sampling intervals starting from 2012 to 2018 were therefore chosen to maximize the period of time covered while still being able to see the emergence and decline of trends in the collected data.

Data (tweets), along with metadata information (ie, user name and user follower count) were collected from public Australian Twitter users when a tweet included at least one of the identified keywords from each respective year. Data were downloaded in the form of CSV (comma separated value) files for each keyword and respective year. Social media users tend to include

multiple hashtags within their posts, which resulted in duplicate tweets being collected. Duplicate tweets within keyword corpora for each year and across keyword corpora from the co-use of hashtags were removed, resulting in the inclusion of only unique tweets [31]. Data were assigned a number in ascending order and 100 tweets from each keyword corpus for each year were randomly selected for analysis, using an online random sequence generator [32]. Selected data were checked by one researcher (KM) to determine eligibility (ie, written in English and relevant to e-cigarettes). If any of the originally selected 100 tweets did not fit the inclusion criteria, further sampling occurred until 100 eligible tweets were reached. If a keyword corpus had less than 100 tweets, all eligible tweets were included. Retweets (tweets reposted by users) were included in this study, which facilitated the understanding of what information was being circulated by Australian users, even if it originated in another country.

Ethical Considerations

A particularly salient concern among researchers is whether social media data should be considered public or private data [33]. Twitter is a social networking service in which users broadcast their opinions and commonly use a hashtag to associate their thoughts on a subject with users on the same subject, and therefore, these data are generally referred to as “public data” [33]. For ethical, privacy, and technical reasons, TrISMA does not collect tweets from private accounts or direct messages; therefore, all data collected in this study were publicly available. This study was approved by the Curtin University Human Research Ethics Committee (approval number: HRE2017-0144).

Developing the Coding Frame

A concept-driven approach (inductive) [34] informed by extant studies [22,23,35-42] was utilized to develop a triaxial coding framework to capture the account users, and the sentiment and theme of the tweets they posted. The coding frame was tested on a random sample of 100 tweets, whereby each tweet was read and assigned codes based upon the concepts presented in the descriptive text, hashtags, and any accompanying images [43]. One researcher (KM) undertook this process in NVivo (v11; QSR International), iteratively revising the coding framework to further refine predefined codes, merge others to create broader codes encompassing several related concepts, and identify new codes arising from the data using a data-driven approach (deductive) [34], which served as a revalidation of earlier coded material [44].

Coding and Analysis

The modified coding framework was transferred to IBM SPSS Statistics (v22; IBM Corp) and applied to the data by the same researcher. The coding descriptor *user category* characterizes the sender of the tweet and typically involved a detailed inspection of the associated Twitter profile, including the profile picture, bio description, follower-to-following ratio, and tweet history (ie, the content of tweets, number of daily tweets, and

ratio of original tweets to retweets) to determine who the user was (Multimedia Appendix 1) [39]. Although data were unique, the poster's of the data were not necessarily so and could be counted multiple times if their data were collected and selected for analysis. The coding descriptor *sentiment* reflects the stance expressed in the tweet toward e-cigarettes and related products or its users, whether positive, negative, or neutral (Multimedia Appendix 2). The coding descriptor *theme* reflects the theme of the actual content conveyed in the tweet (Multimedia Appendix 3). The text of each tweet and/or the Twitter user handle were explored via Twitter's search function to examine the profile of the user and any comments attached to the tweet to assist with understanding its context. URLs embedded within tweets were followed. If the URL was active, it was recorded as linking to either social media (eg, Instagram, Facebook, and YouTube) or a website (eg, retail, news, and blog). Each code within the coding framework was a variable in SPSS that functioned as a stand-alone item and was evaluated as either 1 for *present* or 2 for *absent*. *User category* and *sentiment* were mutually exclusive categories (ie, only one selection could be made per category), while the *theme* of the tweet and links to social media and websites were not. The chi-square test (or Fisher exact test if applicable) was used to examine the variation in the content of tweets between years.

Results

Sample of Posts

In total, 4432 tweets were analyzed. There were 570 (12.86%) tweets in 2012, 1196 (26.99%) in 2014, 1377 (31.07%) in 2016, and 1289 (29.08%) in 2018.

Retweets

Of the sample, 25.86% (1146/4432) were retweets, and of these, 79.23% (908/1146) were categorized as having a positive sentiment toward e-cigarettes. Posts by vape retailers or manufacturers (254/1146, 22.16%), e-cigarette advocates (248/1146, 21.64%), and the general public (219/1146, 19.11%) were most often retweeted. The content of the most frequently retweeted posts reflected advertising or promotion of vaping-related paraphernalia, groups, brands, retailers, or manufacturers (374/1146, 32.64%); posts mentioning an e-cigarette brand (248/1146, 21.64%); and posts discussing regulation or policy (246/1146, 21.47%) and the health and safety of e-cigarettes (204/1146, 17.80%).

Reporting of the following results includes both original tweets and retweets unless otherwise specified.

Sentiment

The vast majority of tweets (3754/4432, 84.70%) reflected positive perceptions toward e-cigarettes and related products or its users. Positive sentiment, however, decreased over time as negative sentiment increased (Table 1).

Table 1. Sentiment of data.

Sentiment	Year				Total (N=4432), n (%)
	2012 (N=570), n (%)	2014 (N=1196), n (%)	2016 (N=1377), n (%)	2018 (N=1289), n (%)	
Positive	515 (90.35)	1041 (87.04)	1197 (86.93)	1001 (77.66)	3754 (84.70)
Neutral	36 (6.32)	69 (5.77)	96 (6.97)	125 (9.70)	326 (7.36)
Negative	19 (3.33)	86 (7.19)	84 (6.10)	163 (12.65)	352 (7.94)

User Category

Vape retailers and manufacturers (1161/4432, 26.20%), the general public (1079/4432, 24.35%), and e-cigarette advocates (1038/4432, 23.42%) posted 73.96% (3278/4432) of the data analyzed (Table 2). The number of tweets posted by vape retailers and manufacturers peaked in 2014 and gradually

declined in subsequent years. Similarly, tweets posted by e-cigarette advocates peaked, however, later in 2016 and declined in 2018. The number of tweets posted by news and media sources and public health professionals, researchers, and academics gradually increased over time. Tweets posted by suspicious (suspected “bot”) accounts progressively declined since 2012.

Table 2. Twitter user category.

User category	Year				Total (N=4432), n (%)
	2012 (N=570), n (%)	2014 (N=1196), n (%)	2016 (N=1377), n (%)	2018 (N=1289), n (%)	
Vape retailer or manufacturer	147 (25.79)	451 (37.71)	310 (22.51)	253 (19.63)	1161 (26.20)
General public	164 (28.77)	303 (25.33)	286 (20.77)	326 (25.29)	1079 (24.35)
E-cigarette advocate	89 (15.61)	235 (19.65)	439 (31.88)	275 (21.33)	1038 (23.42)
News or media source	1 (0.18)	22 (1.84)	48 (3.49)	147 (11.40)	218 (4.92)
Suspected bot	104 (18.25)	54 (4.54)	46 (3.34)	3 (0.23)	207 (4.67)
Other	36 (6.32)	58 (4.85)	73 (5.30)	34 (2.64)	201 (4.54)
Public health professional, researcher, or academic	2 (0.35)	11 (0.92)	35 (2.54)	127 (9.85)	175 (3.95)
Account not active or user suspended	13 (2.28)	46 (3.85)	73 (5.30)	24 (1.86)	156 (3.52)
Consumer advocacy group	13 (2.28)	1 (0.83)	33 (2.40)	50 (3.88)	97 (2.19)
Health or scientific group	0 (0)	6 (0.50)	22 (1.60)	34 (2.64)	62 (1.40)
Medical doctor, nurse, or group	1 (0.18)	7 (0.59)	6 (0.44)	8 (0.62)	22 (0.50)
Government or politician	0 (0)	2 (0.17)	6 (0.44)	8 (0.62)	16 (0.36)

Sentiment by User Category

Tweets by the general public (845/1079, 78.31%), suspected bot accounts (185/207, 89.4%), e-cigarette advocates (1007/1038, 97.01%), consumer advocacy groups (95/97, 98%), and vape retailers and manufacturers (1158/1161, 99.74%) were predominantly positive (Table 3). Tweets posted by health and

scientific groups (32/62, 52%) and medical doctors and nurses (12/22, 54%) were mostly negative, which contrasts with the proportion of positive tweets posted by other members of the public health community (ie, public health professionals, researchers, and academics [106/175, 60.6%]). Tweets by news and media accounts were mostly neutral (97/218, 44.5%).

Table 3. Twitter user category and sentiment of data.

User category	Sentiment			Total, n (%)
	Positive, n (%)	Neutral, n (%)	Negative, n (%)	
Vape retailer or manufacturer	1158 (99.74)	0 (0)	3 (0.26)	1161 (26.20)
Consumer advocacy group	95 (97.94)	1 (1.03)	1 (1.03)	97 (2.19)
E-cigarette advocate	1007 (97.01)	23 (2.22)	8 (0.77)	1038 (23.42)
Suspected bot	185 (89.37)	13 (6.28)	9 (4.35)	207 (4.67)
General public	845 (78.31)	115 (10.66)	119 (11.03)	1079 (24.35)
Other	150 (74.63)	27 (13.43)	24 (11.94)	201 (4.54)
Public health professional, researcher, or academic	106 (60.57)	18 (10.29)	51 (29.14)	175 (3.95)
Government or politician	9 (56.25)	1 (6.25)	6 (37.50)	16 (0.36)
Health or scientific group	19 (30.65)	11 (17.74)	32 (51.61)	62 (1.40)
News or media source	48 (22.02)	97 (44.50)	73 (33.49)	218 (4.92)
Medical doctor, nurse, or group	3 (13.64)	7 (31.82)	12 (54.55)	22 (0.50)
Account not active or user suspended	129 (82.69)	13 (8.33)	14 (8.97)	156 (3.52)
Total	3754 (84.70)	326 (7.36)	352 (7.94)	4432 (100)


Themes Reflected in the Data

The following narrative reflects on some of the most prevalent themes found in the data. Refer to [Multimedia Appendix 4](#) for all themes.

Advertising or Promotion

Almost half (2040/4432, 46.03%) of all data were classified as advertising or promotion. The number of advertising and promotional tweets collected peaked in 2014 and displayed a downward trend in subsequent years ([Table 4](#)). These tweets promoted vaping-related paraphernalia, groups, brands, events, and retailers and manufacturers. Strategies used to further promote vape products included providing coupons, discount offers, multibuys, and giveaways. These strategies were collectively coded as price promotions and were present in 19.46% (397/2040) of tweets categorized as advertising or promotion. In 2016, the number of these tweets collected doubled compared with the number collected in other years. E-cigarette retailers and manufacturers (990/2040, 48.53%) and

e-cigarette advocates (412/2040, 20.20%) posted the largest proportion of advertising and promotional tweets ([Figure 1](#)). Tweets by e-cigarette retailers and manufacturers commonly advertised vaping paraphernalia to purchase as follows:

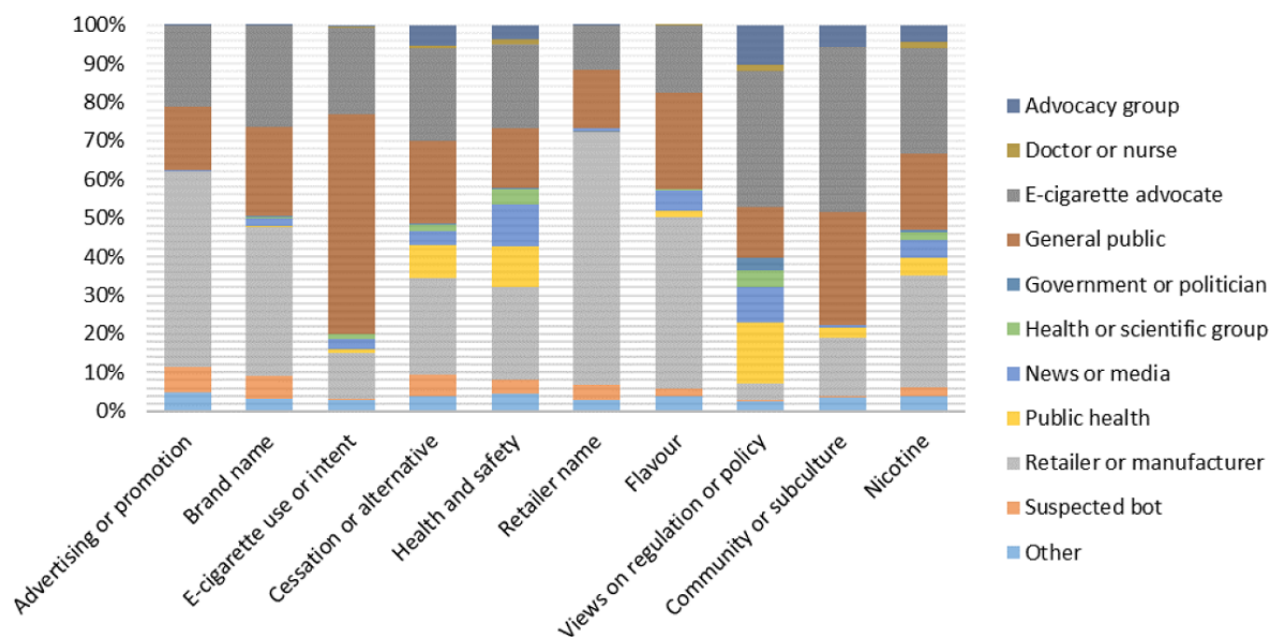
Have you seen the NS Pen by @VandyVape? Slim and elegant design, and good battery capacity for its size... A great starter kit AVAILABLE in store  and online! #VandyVape #VapePen #eCig #VapeKit #Vaping #VapeLife #Soulblu

On the other hand, the general public and e-cigarette advocates were inclined to promote and publicize products they were currently using or testing as follows:

Shout out to @VapoureyesNZ you guys always look after me with my regular order of #alpinecloudco #Kosciuszko & your #heisenberg (which honestly is the best I've tried) #loyalcustomer dhl delivery takes 3days & boom my order is here!! #vapefam #vapegirl #vapoureyesnz THANKYOU 

Table 4. The 10 most prevalent themes.

Tweet content	Year				Total (N=4432), n (%)
	2012 (N=570), n (%)	2014 (N=1196), n (%)	2016 (N=1377), n (%)	2018 (N=1289), n (%)	
Advertising or promotion	268 (47.02)	685 (57.27)	633 (45.97)	436 (33.82)	2040 (46.03)
Price promotion	77 (28.73)	80 (11.68)	152 (24.01)	88 (20.18)	397 (19.46)
Brand name	124 (21.75)	302 (25.25)	448 (32.53)	364 (28.24)	1238 (27.93)
E-cigarette use or intent	76 (13.33)	254 (21.24)	358 (26.00)	282 (21.88)	970 (21.89)
Cessation or alternative	105 (18.42)	182 (15.23)	136 (9.88)	293 (22.75)	716 (16.16)
Positive	100 (95.24)	176 (96.70)	130 (95.59)	274 (93.52)	680 (94.97)
Negative	1 (0.95)	4 (2.20)	2 (1.45)	13 (4.44)	20 (2.79)
Neutral	4 (3.81)	2 (1.14)	4 (2.94)	6 (2.05)	16 (2.24)
Health and safety	67 (11.75)	161 (13.46)	139 (10.09)	314 (24.38)	681 (15.37)
Positive	51 (76.12)	114 (70.81)	91 (65.47)	198 (63.06)	454 (66.66)
Negative	10 (14.93)	36 (22.36)	36 (25.90)	101 (32.17)	183 (26.87)
Neutral	6 (8.96)	11 (6.83)	12 (8.63)	15 (4.77)	44 (6.46)
Retailer name	78 (13.68)	234 (19.57)	136 (9.88)	201 (15.61)	649 (14.64)
Flavor	39 (6.84)	145 (12.12)	139 (10.09)	184 (14.29)	507 (11.44)
Views on regulation or policy	6 (1.05)	45 (3.76)	64 (4.65)	192 (14.91)	307 (6.97)
Liberal	3 (50.00)	36 (80.00)	58 (90.63)	151 (78.65)	248 (80.78)
Cautious	3 (50.00)	6 (13.33)	5 (7.81)	40 (20.83)	54 (17.60)
Neutral	0 (0)	3 (6.66)	1 (1.56)	1 (0.52)	5 (1.63)
Community or subculture	18 (3.16)	48 (4.01)	84 (6.10)	155 (12.03)	305 (6.88)
Nicotine	19 (3.33)	42 (3.51)	89 (6.46)	143 (11.10)	293 (6.61)

Figure 1. User category contribution in the 10 most prevalent themes.

A Smoking Cessation Aid or Tobacco Alternative

Overall, 16.16% (716/4432) of tweets discussed the potential of e-cigarettes to be used for tobacco smoking cessation or used as a tobacco alternative. The vast majority of tweets in this category maintained that e-cigarettes could be used to help tobacco smokers quit or reduce their tobacco consumption (680/716, 95.0%), and were most prevalent in 2018 (Table 4). E-cigarette retailers and manufacturers (176/680, 25.9%), e-cigarette advocates (169/680, 24.9%), and the general public (139/680, 20.4%) contributed the largest proportion of tweets supporting the use of e-cigarettes as a smoking cessation product. For example, one retailer posted the following statement:

Thousands of people loosing [sic] their lives because of #Smoking annually. Why don't you #Vape instead of #Smoking which is much safer, in fact it is not at all harmful. Make a move now! #VapeOn #SteamLite

Health and Safety

Overall, 15.37% (681/4432) of tweets discussed the perceived health and safety benefits (eg, increased physical stamina and financial wellbeing) and consequences (eg, device malfunction and exacerbation of respiratory diseases) of e-cigarette use. The majority (454/681, 66.7%) of these tweets stated the benefits of using e-cigarettes, peaking in 2018. Similarly, the number of negative health and safety tweets increased over time (Table 4). Tweets considering the positive health and safety aspects of e-cigarettes were dominated by vape retailers and manufacturers (158/454, 34.8%) and e-cigarette advocates (120/454, 26.4%). One post was as follows:

I've been smoke free for almost 5 years now, and have had huge improvements in my health, BECAUSE of switching to vaping, that makes me a criminal in Aus [Australia]. I'll take vaping any day over toxic pharma garbage like pills and gums. Inhaling air is potentially harmful, so is ignorance.

On the other hand, those expressing negative views were news and media sources (52/183, 28.4%), the general public (29/183, 15.8%), and public health professionals, researchers, and academics (27/183, 14.8%). One post was as follows:

As vaping products and their promotion become more prevalent, health professionals are warning that e-cigarettes are not as safe as many people believe.

Views on Regulation and Policy

Overall, 6.93% (307/4432) of tweets discussed e-cigarette regulation or policy (Table 4). The majority of the data expressed positive sentiment toward liberal e-cigarette regulation (248/307, 80.8%), and these posts were dominated by e-cigarette advocates (105/248, 42.3%) and public health professionals, researchers, and academics (40/248, 16.1%). One post was as follows:

Long time supporter and campaigner for #vaping I campaigned and worked hard to prevent further restrictions on #vapes Sadly couldn't convince the 3 major parties. Abbreviated policy here <https://www.reasonvic.org.au/policy/#votereason>

Consistent with those supporting liberal regulation or legalization, e-cigarette advocates most often provided commentary that challenged the implementation of restrictive e-cigarette policies, provided testimonies as to why e-cigarette regulation should be relaxed, and challenged other Twitter users expressing antivaping views (123/263, 46.8%). One post was as follows:

Anti- #vaping advocates often compare the lack of absolute safety of #ecigs with accepting the precautionary principle as being applicable. Of course this is facile and silly. They ignore the risk of causing harm by blocking innovation by doing nothing.

Links to Websites and Social Media Platforms

Overall, 44.29% (1963/4432) of posts included at least one embedded URL to an external website. Tweets most frequently included URLs that linked to news (536/1963, 27.31%) and retail websites (415/1963, 21.14%), blogs (326/1963, 16.61%), and scholarly articles and reports (79/1963, 4.02%). Almost half (530/1146, 46.25%) of retweets contained at least one URL that linked to an external website, and the most common were news (169/530, 31.9%) and retail (79/530, 14.9%) websites.

Overall, 18.55% (822/4432) of tweets linked to another social media platform, also known as cross-platform posting. Posts most commonly linked to Instagram (550/822, 66.9%) and Facebook (120/822, 14.6%). Additionally, 22.69% (460/2027) of tweets that were categorized as advertising or promotion were linked to Instagram.

Discussion

Principal Findings

This study analyzed 4432 vaping-related tweets from 2012, 2014, 2016, and 2018, posted and retweeted by Australian users. Analysis of the data indicated that positive sentiment continues to dominate the e-cigarette discourse on Twitter, and the ongoing polarized debate among the public health community is not reflected. Largely, a one-sided perspective is being presented by vape retailers and manufacturers, e-cigarette advocates, the general public, and select public health professionals, researchers, and academics.

Twitter users with vested interests in e-cigarettes (ie, retailers and manufacturers), e-cigarette advocates, and the general public were found to tweet a very high proportion of positive tweets (>70%). News and health-related accounts provided messages that were the least positive and/or neutral; however, these tweets comprised a small proportion of the total sample. Our findings concur with recent studies [4,45]. However, we found that some vocal provaping public health professionals, researchers, and academics are skewing the conversation, which is not the view of the wider Australian and international public health communities [46].

E-cigarette advocates, along with a small number of vocal public health professionals, researchers, and academics, were predominately positive in their discussions and were found to challenge other Twitter users who expressed antivaping views

or were deemed to be “misrepresenting the facts” concerning e-cigarettes. Some Australian public health academics, who do not support the use of e-cigarettes until they are proven to be a safe and efficacious smoking cessation aid, have documented their relentless struggles with provaping advocates on Twitter [47,48], with one stating that the collective abuse received from other interest groups, such as smokers’ rights advocates, antivaccinationists, and climate change denialists, pales into insignificance compared with the volume of abuse received from vaping advocates. Several tactics were used by e-cigarette advocates to communicate their beliefs, including attempts to frame e-cigarettes as safer than tobacco cigarettes, imply that federal government agencies lack sufficient competence or evidence for the policies they endorse about vaping, and denounce as propaganda “gateway” claims of youth progressing from e-cigarettes to tobacco cigarettes. Australian e-cigarette advocates were also found to use a range of tropes to justify their support for vaping, which have been identified in international research [49], including encouraging an “us versus them” mentality, attacking those opposed to e-cigarettes, relying on personal anecdotal evidence, minimizing side effects, normalizing use, and emphasizing the benefits of e-cigarettes. These tactics may impact the proportion of the public health community and other Twitter users who are willing to express contradictory views [50], thereby skewing the commentary and possibly shaping the views and risk perceptions of vulnerable populations such as youth [51]. This notion is supported by our findings, with only 7.94% (352/4432) of tweets categorized as negative and 7.36% (326/4432) as neutral.

Groups who are usually viewed as health experts or opinion leaders, such as medical doctors and nurses, reputable scientific organizations, and government organizations and politicians, collectively posted only 2.26% (100/4432) of tweets analyzed in this study. A great deal of health information is now distributed and sourced online, which has resulted in less of a reliance upon these traditional knowledge brokers in offline settings [52]. In the online environment, “the multiplicity of sources involved in information dissemination, their possible anonymity, the absence of standards for information quality, the ease in manipulating and altering content, the lack of clarity of the context, and the presence of many potential targets of credibility evaluation (ie, the content, the source, and the medium)” [52] make the assessment of information an often complex task. As a result, individuals are now burdened with the responsibility of information evaluation that was once the responsibility of professional gatekeepers [53]. The health literacy levels of the Australian population are generally low [54,55], and investigating methods to assist internet users in assessing the credibility of online information is therefore particularly important, as well as the dissemination of evidence-based information by respected experts and opinion leaders.

Our results support previous vaping-related Twitter investigations reporting that the Twitter landscape is dominated by tweets from industry and commercial users championing e-cigarettes as a healthier tobacco alternative and as a successful cessation aid [11,23,41]. These views are contrary to Australia’s regulatory approach to e-cigarettes, which aims to safeguard

public health and control the drivers of negative e-cigarette use (ie, use among youth and nonsmokers and unfettered marketing) [56]. Australia is a signatory to the World Health Organization Framework Convention on Tobacco Control, which is designed to protect public health policies from commercial and other vested interests [57]. Until there is adequate evidence that e-cigarettes are safe and an efficacious smoking cessation product, they should not be promoted as such.

A substantial proportion of tweets used sales techniques, such as price promotions, which have historically been successfully employed by the tobacco industry, to influence cigarette uptake and consumption [58]. These findings have implications for the marketing of e-cigarettes on other social media platforms, in particular Instagram, owing to the level of cross-platform interaction found in this investigation, which is worth further examination. Given the substantial youth presence on social media, the marketing of e-cigarettes on these platforms may entice nonsmokers and youth, in particular, to experiment with and initiate vaping [59]. Data from the most recent National Drug Strategy Household Survey [60] reports 11.3% of Australians aged over 14 years have ever used and 2.5% currently use e-cigarettes, with increases of 2.5% and 1.3%, respectively, since 2016. These increases occurred in both smokers and nonsmokers and contrast with Australian combustible smoking rates, which have continued to decline over the last 30 years. The most frequent reason for using e-cigarettes reported by people over 14 years was “out of curiosity” (54.2%). Others (22.8%) cited using e-cigarettes because they perceived them to be less harmful than tobacco cigarettes (19.2% in 2016), and 10.1% believed vaping to be more socially acceptable than tobacco smoking (6.0% in 2016). Further, 26.9% of respondents reported that they obtained their e-cigarette products online (Australian retailer 12.5%, overseas retailer 11.1%, unknown origin 3.3%), a trend that should be closely monitored [61].

Implications for Public Health

The practice of public health relies on evidence and clear communication between practitioners and the communities they serve [62], and in the absence of balanced evidence-based dialogue, personal opinion and marketing of e-cigarettes dominate the Twitter landscape. The scientific community is generally still a highly trusted source of information [63]. However, if disinformation and misinformation continue to be disseminated online, this could pose a legitimate threat to public health, as evidenced by the propaganda circulated during the 2014 Ebola outbreak [64] and 2020 coronavirus pandemic [65]. These realities require action, with a combination of regulation and health groups contributing to peer reviewed evidence and working with social media platforms to recognise and abate health information and disinformation. Offline, medical, and public health practitioners and researchers can work to dispel misinformation and disinformation directly through their built and trusted relationships and networks [63].

There are known and trusted strategies for addressing misinformation and disinformation in the field of health communication, but more research is needed to fully understand how well these translate into a social media context, how this

information spreads online, and how to develop data-driven solutions to this growing threat [62,63,66]. It is important to assess the extent of misinformation and disinformation related to vaping, considering its potential to generate negative public health consequences. Deployment of innovative methods on a broader scale is needed, including natural language processing, assisted data mining, social network analysis, and online experimentation to track the spread of this content [62]. Surveillance endeavors must be agile and adaptable and require both researchers and practitioners to establish relationships with computer science professionals to stay abreast of the rapidly changing technology.

Limitations

Coding using the triaxial classification system relied on the researchers' subjective assessment, although the investigation of each tweet and user profile was particularly thorough and included examination of associated commentary to facilitate the understanding of the tweet context and examination of the user's profile page including profile photo, bio, and recent activity. TrISMA's programmed bot filtering processes were relied upon to remove data posted by questionable accounts. However, through our manual investigation some Twitter users were signposted as "suspected bot" accounts. Bot accounts have become more sophisticated over time, better aligning with human activity on Twitter [67], and as such, it was particularly difficult in some instances to ascertain whether some accounts were genuine users or not.

Acknowledgments

This work was supported by a Healthway Exploratory Research Grant (grant number 32803) and an Australian Government Research Training Program Scholarship. The scholarship is provided by the Commonwealth of Australia to support the general living costs for students (KM) undertaking doctoral research studies. The funders had no role in the design of the study; in the collection, analysis, or interpretation of data; in the writing of the manuscript; or in the decision to publish the results. This research was also supported by infrastructure provided through the Australian Research Council-funded project TrISMA (Tracking Infrastructure for Social Media Analysis) (LIEF grant LE140100148). We would like to acknowledge Dr Kevin Chai, Dr Alkim Ozaygen, and Dr Yun Zhao from Curtin University, for their assistance with data collection and statistical analysis. We would also like to thank the Cancer Council Western Australia, Australian Council on Smoking and Health, Public Health Advocacy Institute of Western Australia, and the Royal Australian College of General Practitioners Western Australia for their contributions as members of the study's advisory committee. They provided advice to the research team to help guide the implementation of the project, use of generated data, and dissemination of the research findings.

Authors' Contributions

Funding acquisition: JJ, BM, TL, KW, and KM; conceptualization: KM, JJ, BM, TL, and KW; project administration: KM; supervision: JJ, BM, and TL; data curation: KM; formal analysis: KM; methodology: KM, JJ, BM, TL, and KW; Writing—original draft: KM; Writing—review and editing: BF, JJ, BM, KW, and TL.

Conflicts of Interest

BF is a member of the NHMRC Electronic Cigarettes Working Committee (May 2020). She has received consulting payment for e-cigarette policy review for the NSW National Heart Foundation (December 2019). She had travel expenses (flight and registration) reimbursed to attend Oceania Tobacco Control Conference 2017 to present on e-cigarette and cessation. She provided her opinion (unpaid) at Australian Parliament's Standing Committee on Health, Aged Care and Sport public hearing into the Use and Marketing of Electronic Cigarettes and Personal Vaporisers (September 8, 2017). She led a contract on e-cigarette regulation in Australia for the Commonwealth Department of Health (2016). She had travel expenses reimbursed by National Taiwan University for presenting on e-cigarette regulation (2016). The other authors have no conflicts to declare.

Multimedia Appendix 1

Coding framework: user category.

[\[DOCX File, 15 KB - publichealth_v6i4e17543_app1.docx\]](#)

Multimedia Appendix 2

Coding framework: sentiment.

[\[DOCX File, 12 KB - publichealth_v6i4e17543_app2.docx\]](#)

Multimedia Appendix 3

Coding framework: themes.

[\[DOCX File, 21 KB - publichealth_v6i4e17543_app3.docx\]](#)

Multimedia Appendix 4

Results: all themes.

[\[DOCX File , 25 KB - publichealth_v6i4e17543_app4.docx \]](#)**References**

1. E-cigarette market - Growth, trends and forecast (2020-2025). Mordor Intelligence. 2019. URL: <https://www.mordorintelligence.com/industry-reports/global-e-cigarettes-market-industry> [accessed 2020-10-06]
2. Herzog B. E-cigs revolutionizing the tobacco industry. Convenience Store News. 2013. URL: <https://csnews.com/e-cigs-revolutionizing-tobacco-industry> [accessed 2020-10-05]
3. Huang J, Duan Z, Kwok J, Binns S, Vera LE, Kim Y, et al. Vaping versus JUULing: how the extraordinary growth and marketing of JUUL transformed the US retail e-cigarette market. *Tob Control* 2019 Mar;28(2):146-151 [FREE Full text] [doi: [10.1136/tobaccocontrol-2018-054382](https://doi.org/10.1136/tobaccocontrol-2018-054382)] [Medline: [29853561](https://pubmed.ncbi.nlm.nih.gov/29853561/)]
4. McCausland K, Maycock B, Leaver T, Jancey J. The Messages Presented in Electronic Cigarette-Related Social Media Promotions and Discussion: Scoping Review. *J Med Internet Res* 2019 Feb 05;21(2):e11953 [FREE Full text] [doi: [10.2196/11953](https://doi.org/10.2196/11953)] [Medline: [30720440](https://pubmed.ncbi.nlm.nih.gov/30720440/)]
5. Zhan Y, Liu R, Li Q, Leischow SJ, Zeng DD. Identifying Topics for E-Cigarette User-Generated Contents: A Case Study From Multiple Social Media Platforms. *J Med Internet Res* 2017 Jan 20;19(1):e24 [FREE Full text] [doi: [10.2196/jmir.5780](https://doi.org/10.2196/jmir.5780)] [Medline: [28108428](https://pubmed.ncbi.nlm.nih.gov/28108428/)]
6. Zhao Y, Zhang J. Consumer health information seeking in social media: a literature review. *Health Info Libr J* 2017 Dec;34(4):268-283. [doi: [10.1111/hir.12192](https://doi.org/10.1111/hir.12192)] [Medline: [29045011](https://pubmed.ncbi.nlm.nih.gov/29045011/)]
7. Allem J, Ferrara E. Could Social Bots Pose a Threat to Public Health? *Am J Public Health* 2018 Aug;108(8):1005-1006. [doi: [10.2105/AJPH.2018.304512](https://doi.org/10.2105/AJPH.2018.304512)] [Medline: [29995482](https://pubmed.ncbi.nlm.nih.gov/29995482/)]
8. Allem J, Cruz TB, Unger JB, Toruno R, Herrera J, Kirkpatrick MG. Return of cartoon to market e-cigarette-related products. *Tob Control* 2019 Sep;28(5):555-557 [FREE Full text] [doi: [10.1136/tobaccocontrol-2018-054437](https://doi.org/10.1136/tobaccocontrol-2018-054437)] [Medline: [30049688](https://pubmed.ncbi.nlm.nih.gov/30049688/)]
9. Number of monthly active Twitter users worldwide from 1st quarter 2010 to 4th quarter 2018 (in millions). Statista. 2019. URL: <https://www.statista.com/statistics/282087/number-of-monthly-active-twitter-users/> [accessed 2019-12-16]
10. Dai H, Hao J. Mining social media data for opinion polarities about electronic cigarettes. *Tob Control* 2017 Mar;26(2):175-180. [doi: [10.1136/tobaccocontrol-2015-052818](https://doi.org/10.1136/tobaccocontrol-2015-052818)] [Medline: [26980151](https://pubmed.ncbi.nlm.nih.gov/26980151/)]
11. Kim AE, Hopper T, Simpson S, Nonnemaker J, Lieberman AJ, Hansen H, et al. Using Twitter Data to Gain Insights into E-cigarette Marketing and Locations of Use: An Inveillance Study. *J Med Internet Res* 2015 Nov 06;17(11):e251 [FREE Full text] [doi: [10.2196/jmir.4466](https://doi.org/10.2196/jmir.4466)] [Medline: [26545927](https://pubmed.ncbi.nlm.nih.gov/26545927/)]
12. Kwon M, Park E. Perceptions and Sentiments About Electronic Cigarettes on Social Media Platforms: Systematic Review. *JMIR Public Health Surveill* 2020 Jan 15;6(1):e13673 [FREE Full text] [doi: [10.2196/13673](https://doi.org/10.2196/13673)] [Medline: [31939747](https://pubmed.ncbi.nlm.nih.gov/31939747/)]
13. E-cigarettes. Quit. 2017. URL: <https://www.quit.org.au/resources/policy-advocacy/policy/e-cigarettes/> [accessed 2019-06-24]
14. Electronic cigarettes. Therapeutic Goods Administration. 2019. URL: <https://www.tga.gov.au/community-qa/electronic-cigarettes> [accessed 2020-05-15]
15. NicoPharm. URL: <http://nicopharm.com.au/> [accessed 2019-11-06]
16. Prohibited goods - Tobacco. Australian Border Force. 2020. URL: <https://www.abf.gov.au/importing-exporting-and-manufacturing/prohibited-goods/categories/tobacco> [accessed 2020-10-06]
17. Greenhalgh E, Grace C, Scollo M. 18B: Electronic cigarettes (e-cigarettes). Legal status in Australia. *Tobacco in Australia: Facts and Issues*. 2018. URL: <https://www.tobaccoinaustralia.org.au/chapter-18-harm-reduction/indepth-18b-e-cigarettes/18b-9-legal-status> [accessed 2019-11-06]
18. Digital 2019: Australia. DataReportal. 2019. URL: <https://datareportal.com/reports/digital-2019-australia?rq=australia> [accessed 2020-03-18]
19. Bruns A, Stieglitz S. Quantitative Approaches to Comparing Communication Patterns on Twitter. *Journal of Technology in Human Services* 2012 Jul;30(3-4):160-185. [doi: [10.1080/15228835.2012.744249](https://doi.org/10.1080/15228835.2012.744249)]
20. Emery SL, Vera L, Huang J, Szczypka G. Wanna know about vaping? Patterns of message exposure, seeking and sharing information about e-cigarettes across media platforms. *Tob Control* 2014 Jul 16;23 Suppl 3(suppl 3):iii17-iii25 [FREE Full text] [doi: [10.1136/tobaccocontrol-2014-051648](https://doi.org/10.1136/tobaccocontrol-2014-051648)] [Medline: [24935893](https://pubmed.ncbi.nlm.nih.gov/24935893/)]
21. Pechmann C, Pan L, Delucchi K, Lakon CM, Prochaska JJ. Development of a Twitter-based intervention for smoking cessation that encourages high-quality social media interactions via automessages. *J Med Internet Res* 2015 Feb 23;17(2):e50 [FREE Full text] [doi: [10.2196/jmir.3772](https://doi.org/10.2196/jmir.3772)] [Medline: [25707037](https://pubmed.ncbi.nlm.nih.gov/25707037/)]
22. Cole-Lewis H, Pugatch J, Sanders A, Varghese A, Posada S, Yun C, et al. Social Listening: A Content Analysis of E-Cigarette Discussions on Twitter. *J Med Internet Res* 2015 Oct 27;17(10):e243 [FREE Full text] [doi: [10.2196/jmir.4969](https://doi.org/10.2196/jmir.4969)] [Medline: [26508089](https://pubmed.ncbi.nlm.nih.gov/26508089/)]
23. Huang J, Kornfield R, Szczypka G, Emery SL. A cross-sectional examination of marketing of electronic cigarettes on Twitter. *Tob Control* 2014 Jul;23 Suppl 3:iii26-iii30 [FREE Full text] [doi: [10.1136/tobaccocontrol-2014-051551](https://doi.org/10.1136/tobaccocontrol-2014-051551)] [Medline: [24935894](https://pubmed.ncbi.nlm.nih.gov/24935894/)]

24. Bruns A, Burgess J, Banks J, Tjondronegoro D, Dreiling A, Hartley J, et al. TrISMA: Tracking Infrastructure for Social Media Analysis. 2016. URL: <http://trisma.org/> [accessed 2019-06-01]
25. Chu K, Allem J, Cruz TB, Unger JB. Vaping on Instagram: cloud chasing, hand checks and product placement. *Tob Control* 2016 Sep;26(5):575-578 [FREE Full text] [doi: [10.1136/tobaccocontrol-2016-053052](https://doi.org/10.1136/tobaccocontrol-2016-053052)] [Medline: [27660111](https://pubmed.ncbi.nlm.nih.gov/27660111/)]
26. Laestadius LI, Wahl MM, Cho YI. #Vapelife: An Exploratory Study of Electronic Cigarette Use and Promotion on Instagram. *Subst Use Misuse* 2016 Oct 14;51(12):1669-1673. [doi: [10.1080/10826084.2016.1188958](https://doi.org/10.1080/10826084.2016.1188958)] [Medline: [27484191](https://pubmed.ncbi.nlm.nih.gov/27484191/)]
27. Laestadius LI, Wahl MM, Pokhrel P, Cho YI. From Apple to Werewolf: A content analysis of marketing for e-liquids on Instagram. *Addict Behav* 2019 Apr;91:119-127 [FREE Full text] [doi: [10.1016/j.addbeh.2018.09.008](https://doi.org/10.1016/j.addbeh.2018.09.008)] [Medline: [30253933](https://pubmed.ncbi.nlm.nih.gov/30253933/)]
28. Lee AS, Hart JL, Sears CG, Walker KL, Siu A, Smith C. A picture is worth a thousand words: Electronic cigarette content on Instagram and Pinterest. *Tob Prev Cessat* 2017 Jul;3 [FREE Full text] [doi: [10.18332/tpc/74709](https://doi.org/10.18332/tpc/74709)] [Medline: [28815224](https://pubmed.ncbi.nlm.nih.gov/28815224/)]
29. Cortese DK, Szczypka G, Emery S, Wang S, Hair E, Vallone D. Smoking Selfies: Using Instagram to Explore Young Women's Smoking Behaviors. *Social Media + Society* 2018 Aug 07;4(3):205630511879076-205630511879078. [doi: [10.1177/2056305118790762](https://doi.org/10.1177/2056305118790762)]
30. Ritter S. Heating Up the Debate: E-cigarettes and Instagram. London, Ontario, Canada: The University of Western Ontario; 2015:1-114.
31. Unger JB, Escobedo P, Allem J, Soto DW, Chu K, Cruz T. Perceptions of Secondhand E-Cigarette Aerosol Among Twitter Users. *Tob Regul Sci* 2016 Apr;2(2):146-152 [FREE Full text] [doi: [10.18001/TRS.2.2.5](https://doi.org/10.18001/TRS.2.2.5)] [Medline: [28090560](https://pubmed.ncbi.nlm.nih.gov/28090560/)]
32. RANDOM.ORG. 2019. URL: <https://www.random.org/sequences/> [accessed 2019-09-10]
33. Townsend L, Wallace C. Social media research: A guide to ethics. The University of Aberdeen. 2016. URL: https://www.gla.ac.uk/media/Media_487729_smx.pdf [accessed 2020-10-06]
34. Schreier M. Qualitative Content Analysis in Practice. London: SAGE; 2012.
35. Allem J, Escobedo P, Chu K, Soto DW, Cruz TB, Unger JB. Campaigns and counter campaigns: reactions on Twitter to e-cigarette education. *Tob Control* 2017 Mar;26(2):226-229 [FREE Full text] [doi: [10.1136/tobaccocontrol-2015-052757](https://doi.org/10.1136/tobaccocontrol-2015-052757)] [Medline: [26956467](https://pubmed.ncbi.nlm.nih.gov/26956467/)]
36. Jo CL, Kornfield R, Kim Y, Emery S, Ribisl KM. Price-related promotions for tobacco products on Twitter. *Tob Control* 2016 Jul;25(4):476-479 [FREE Full text] [doi: [10.1136/tobaccocontrol-2015-052260](https://doi.org/10.1136/tobaccocontrol-2015-052260)] [Medline: [26130449](https://pubmed.ncbi.nlm.nih.gov/26130449/)]
37. Sowles SJ, Krauss MJ, Connolly S, Cavazos-Rehg PA. A Content Analysis of Vaping Advertisements on Twitter, November 2014. *Prev Chronic Dis* 2016 Sep 29;13:E139 [FREE Full text] [doi: [10.5888/pcd13.160274](https://doi.org/10.5888/pcd13.160274)] [Medline: [27685432](https://pubmed.ncbi.nlm.nih.gov/27685432/)]
38. Ayers JW, Leas EC, Allem J, Benton A, Dredze M, Althouse BM, et al. Why do people use electronic nicotine delivery systems (electronic cigarettes)? A content analysis of Twitter, 2012-2015. *PLoS One* 2017;12(3):e0170702 [FREE Full text] [doi: [10.1371/journal.pone.0170702](https://doi.org/10.1371/journal.pone.0170702)] [Medline: [28248987](https://pubmed.ncbi.nlm.nih.gov/28248987/)]
39. Harris JK, Moreland-Russell S, Choucair B, Mansour R, Staub M, Simmons K. Tweeting for and against public health policy: response to the Chicago Department of Public Health's electronic cigarette Twitter campaign. *J Med Internet Res* 2014 Oct 16;16(10):e238 [FREE Full text] [doi: [10.2196/jmir.3622](https://doi.org/10.2196/jmir.3622)] [Medline: [25320863](https://pubmed.ncbi.nlm.nih.gov/25320863/)]
40. Kavuluru R, Sabbir AK. Toward automated e-cigarette surveillance: Spotting e-cigarette proponents on Twitter. *J Biomed Inform* 2016 Jun;61:19-26 [FREE Full text] [doi: [10.1016/j.jbi.2016.03.006](https://doi.org/10.1016/j.jbi.2016.03.006)] [Medline: [26975599](https://pubmed.ncbi.nlm.nih.gov/26975599/)]
41. van der Tempel J, Noormohamed A, Schwartz R, Norman C, Malas M, Zawertailo L. Vape, quit, tweet? Electronic cigarettes and smoking cessation on Twitter. *Int J Public Health* 2016 Mar;61(2):249-256. [doi: [10.1007/s00038-016-0791-2](https://doi.org/10.1007/s00038-016-0791-2)] [Medline: [26841895](https://pubmed.ncbi.nlm.nih.gov/26841895/)]
42. Allem J, Ferrara E, Uppu SP, Cruz TB, Unger JB. E-Cigarette Surveillance With Social Media Data: Social Bots, Emerging Topics, and Trends. *JMIR Public Health Surveill* 2017 Dec 20;3(4):e98 [FREE Full text] [doi: [10.2196/publichealth.8641](https://doi.org/10.2196/publichealth.8641)] [Medline: [29263018](https://pubmed.ncbi.nlm.nih.gov/29263018/)]
43. Highfield T, Leaver T. A methodology for mapping Instagram hashtags. *FM* 2014 Dec 26;20(1):1-11. [doi: [10.5210/fm.v20i1.5563](https://doi.org/10.5210/fm.v20i1.5563)]
44. Elliott V. Thinking about the coding process in qualitative data analysis. *The Qualitative Report*. 2018. URL: <https://nsuworks.nova.edu/tqr/vol23/iss11/14> [accessed 2020-03-18]
45. Ayers JW, Dredze M, Leas EC, Caputi TL, Allem J, Cohen JE. Next generation media monitoring: Global coverage of electronic nicotine delivery systems (electronic cigarettes) on Bing, Google and Twitter, 2013-2018. *PLoS One* 2018;13(11):e0205822 [FREE Full text] [doi: [10.1371/journal.pone.0205822](https://doi.org/10.1371/journal.pone.0205822)] [Medline: [30388126](https://pubmed.ncbi.nlm.nih.gov/30388126/)]
46. Greenhalgh E, Scollo M. 18B: Electronic cigarettes (e-cigarettes). Key Australian and international position statements on e-cigarettes, health, and options for regulation. *Tobacco in Australia: Facts and Issues*. 2019. URL: <https://www.tobaccoinaustralia.org.au/chapter-18-harm-reduction/indepth-18b-e-cigarettes/18b-10-position-statements#x18> [accessed 2019-11-06]
47. Chapman S. On-line abuse and trolling by pro-tobacco and vaping activists. The University of Sydney eScholarship Repository. 2018. URL: <https://ses.library.usyd.edu.au/handle/2123/18483> [accessed 2019-12-16]
48. Daube M. Targets and abuse: the price public health campaigners pay. *Med J Aust* 2015 Apr 06;202(6):294-295. [doi: [10.5694/mja15.00059](https://doi.org/10.5694/mja15.00059)] [Medline: [25832143](https://pubmed.ncbi.nlm.nih.gov/25832143/)]

49. Martinez L. Examining Twitter conversations about electronic nicotine delivery systems (ENDS): A position paper for Specialist Meeting on Human Dynamics in the Mobile Age. San Diego State University. 2018. URL: <https://socialmedia.sdsu.edu/wp-content/uploads/2018/07/Martinez-NSF-Position-Paper-2018.pdf> [accessed 2019-12-16]
50. Fairchild AL, Bayer R, Lee JS. The E-Cigarette Debate: What Counts as Evidence? *Am J Public Health* 2019 Jul;109(7):1000-1006. [doi: [10.2105/AJPH.2019.305107](https://doi.org/10.2105/AJPH.2019.305107)] [Medline: [31095415](https://pubmed.ncbi.nlm.nih.gov/31095415/)]
51. Martinez L, Tsou M, Spitzberg B. A Case Study in Belief Surveillance, Sentiment Analysis, and Identification of Informational Targets for E-Cigarettes Interventions. In: Proceedings of the 10th International Conference on Social Media and Society. 2019 Presented at: SMSociety '19: International Conference on Social Media and Society; July 2019; Toronto, ON, Canada p. 15-23. [doi: [10.1145/3328529.3328540](https://doi.org/10.1145/3328529.3328540)]
52. Eysenbach G. Credibility of health information and digital media: New perspectives and implications for youth. In: Metzger M, Flanagin A, editors. *Digital Media, Youth, and Credibility*. Cambridge, MA: The MIT Press; 2008:123-154.
53. Flanagin A, Metzger M. Digital media and youth: Unparalleled opportunity and unprecedented responsibility. In: Metzger M, Flanagin A, editors. *Digital Media, Youth, and Credibility*. Cambridge, MA: The MIT Press; 2008:5-28.
54. National Health Survey: Health literacy. Australian Bureau of Statistics. 2019. URL: <https://www.abs.gov.au/statistics/health/health-conditions-and-risks/national-health-survey-health-literacy/latest-release> [accessed 2020-10-06]
55. 4228.0 - Adult Literacy and Life Skills Survey, Summary Results, Australia, 2006. Australian Bureau of Statistics. 2008. URL: [https://www.abs.gov.au/AUSSTATS/abs@.nsf/Lookup/4228.0Main+Features+2006%20\(Reissue\)?OpenDocument](https://www.abs.gov.au/AUSSTATS/abs@.nsf/Lookup/4228.0Main+Features+2006%20(Reissue)?OpenDocument) [accessed 2020-07-16]
56. Policy and regulatory approach to electronic cigarettes (e-cigarettes) in Australia. Australian Government Department of Health. 2019. URL: <https://www.health.gov.au/resources/publications/policy-and-regulatory-approach-to-electronic-cigarettes-e-cigarettes-in-australia> [accessed 2020-09-10]
57. WHO Framework Convention on Tobacco Control. URL: <http://www.who.int/fctc/en/> [accessed 2020-10-06]
58. Cummings KM, Hyland A, Lewit E, Shopland D. Use of discount cigarettes by smokers in 20 communities in the United States, 1988-1993. *Tob Control* 1997;6 Suppl 2:S25-S30 [FREE Full text] [doi: [10.1136/tc.6.suppl_2.s25](https://doi.org/10.1136/tc.6.suppl_2.s25)] [Medline: [9583649](https://pubmed.ncbi.nlm.nih.gov/9583649/)]
59. Amin S, Dunn AG, Laranjo L. Social Influence in the Uptake and Use of Electronic Cigarettes: A Systematic Review. *Am J Prev Med* 2020 Jan;58(1):129-141. [doi: [10.1016/j.amepre.2019.08.023](https://doi.org/10.1016/j.amepre.2019.08.023)] [Medline: [31761515](https://pubmed.ncbi.nlm.nih.gov/31761515/)]
60. National Drug Strategy Household Survey 2019. Australian Institute of Health and Welfare. 2020. URL: <https://www.aihw.gov.au/getmedia/3564474e-f7ad-461c-b918-7f8de03d1294/aihw-phe-270-NDSHS-2019.pdf.aspx?inline=true> [accessed 2020-07-21]
61. Amin S, Dunn AG, Laranjo L. Exposure to e-cigarette information and advertising in social media and e-cigarette use in Australia: A mixed methods study. *Drug Alcohol Depend* 2020 Jun 13;213:108112. [doi: [10.1016/j.drugalcdep.2020.108112](https://doi.org/10.1016/j.drugalcdep.2020.108112)] [Medline: [32574981](https://pubmed.ncbi.nlm.nih.gov/32574981/)]
62. Jamison AM, Broniatowski DA, Quinn SC. Malicious Actors on Twitter: A Guide for Public Health Researchers. *Am J Public Health* 2019 May;109(5):688-692. [doi: [10.2105/AJPH.2019.304969](https://doi.org/10.2105/AJPH.2019.304969)] [Medline: [30896994](https://pubmed.ncbi.nlm.nih.gov/30896994/)]
63. Chou WS, Oh A, Klein WM. Addressing Health-Related Misinformation on Social Media. *JAMA* 2018 Dec 18;320(23):2417-2418. [doi: [10.1001/jama.2018.16865](https://doi.org/10.1001/jama.2018.16865)] [Medline: [30428002](https://pubmed.ncbi.nlm.nih.gov/30428002/)]
64. Oyeyemi SO, Gabarron E, Wynn R. Ebola, Twitter, and misinformation: a dangerous combination? *BMJ* 2014 Oct 14;349:g6178. [doi: [10.1136/bmj.g6178](https://doi.org/10.1136/bmj.g6178)] [Medline: [25315514](https://pubmed.ncbi.nlm.nih.gov/25315514/)]
65. Kouzy R, Abi Jaoude J, Kraitem A, El Alam MB, Karam B, Adib E, et al. Coronavirus Goes Viral: Quantifying the COVID-19 Misinformation Epidemic on Twitter. *Cureus* 2020 Mar 13;12(3):e7255 [FREE Full text] [doi: [10.7759/cureus.7255](https://doi.org/10.7759/cureus.7255)] [Medline: [32292669](https://pubmed.ncbi.nlm.nih.gov/32292669/)]
66. Wang Y, McKee M, Torbica A, Stuckler D. Systematic Literature Review on the Spread of Health-related Misinformation on Social Media. *Soc Sci Med* 2019 Nov;240:112552 [FREE Full text] [doi: [10.1016/j.socscimed.2019.112552](https://doi.org/10.1016/j.socscimed.2019.112552)] [Medline: [31561111](https://pubmed.ncbi.nlm.nih.gov/31561111/)]
67. Tucker P. Twitter bots are becoming more human-like: Study. *Defense One*. 2019. URL: <https://www.defenseone.com/technology/2019/09/twitter-bots-are-becoming-more-human-study/159697/> [accessed 2019-12-16]

Abbreviations

TrISMA: Tracking Infrastructure for Social Media Analysis

Edited by G Eysenbach, R Kukafka; submitted 19.12.19; peer-reviewed by JP Allem, L Vera; comments to author 03.03.20; revised version received 18.03.20; accepted 12.09.20; published 14.10.20.

Please cite as:

McCausland K, Maycock B, Leaver T, Wolf K, Freeman B, Jancey J

E-Cigarette Advocates on Twitter: Content Analysis of Vaping-Related Tweets

JMIR Public Health Surveill 2020;6(4):e17543

URL: <http://publichealth.jmir.org/2020/4/e17543/>

doi: [10.2196/17543](https://doi.org/10.2196/17543)

PMID: [33052130](https://pubmed.ncbi.nlm.nih.gov/33052130/)

©Kahlia McCausland, Bruce Maycock, Tama Leaver, Katharina Wolf, Becky Freeman, Jonine Jancey. Originally published in JMIR Public Health and Surveillance (<http://publichealth.jmir.org>), 14.10.2020. This is an open-access article distributed under the terms of the Creative Commons Attribution License (<https://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in JMIR Public Health and Surveillance, is properly cited. The complete bibliographic information, a link to the original publication on <http://publichealth.jmir.org>, as well as this copyright and license information must be included.

Original Paper

Electronic Cigarette–Related Contents on Instagram: Observational Study and Exploratory Analysis

Yankun Gao¹, PhD; Zidian Xie¹, PhD; Li Sun²; Chenliang Xu², PhD; Dongmei Li¹, PhD

¹University of Rochester Medical Center, Rochester, NY, United States

²University of Rochester, Rochester, NY, United States

Corresponding Author:

Dongmei Li, PhD

University of Rochester Medical Center

265 Crittenden Boulevard CU 420708

Rochester, NY, 14642-0708

United States

Phone: 1 5852767285

Fax: 1 (585) 276 1122

Email: Dongmei_Li@urmc.rochester.edu

Abstract

Background: Instagram is a popular social networking platform for users to upload pictures sharing their experiences. Instagram has been widely used by vaping companies and stores to promote electronic cigarettes (e-cigarettes), as well as by public health entities to communicate the risks of e-cigarette use (vaping) to the public.

Objective: We aimed to characterize current vaping-related content on Instagram through descriptive analyses.

Methods: From Instagram, 42,951 posts were collected using vaping-related hashtags in November 2019. The posts were grouped as (1) pro-vaping, (2) vaping warning, (3) neutral to vaping, and (4) not related to vaping based on the attitudes to vaping expressed within the posts. From these Instagram posts and the corresponding 18,786 unique Instagram user accounts, 200 pro-vaping and 200 vaping-warning posts as well as 200 pro-vaping and 200 vaping-warning user accounts were randomly selected for hand coding. Furthermore, follower counts and media counts of the Instagram user accounts as well as the “like” counts and hashtags of the posts were compared between pro-vaping and vaping-warning groups.

Results: There were more posts in the pro-vaping group (41,412 posts) than there were in the vaping-warning group (1539 posts). The majority of pro-vaping images were product display images (163/200, 81.5%), and the most popular image type in vaping-warning posts was educational (95/200, 47.5%). The highest proportion of pro-vaping user account type was vaping store (110/189, 58.1%), and the store account type had the highest mean number of posts (10.33 posts/account). The top 3 vaping-warning user account types were personal (79/155, 51%), vaping-warning community (37/155, 23.9%), and community (35/155, 22.6%), of which the vaping-warning community had the highest mean number of posts (3.68 posts/account). Pro-vaping user accounts had more followers (median 850) and media (median 232) than vaping-warning user accounts had (follower count: median 191; media count: 92). Pro-vaping posts had more “likes” (median 22) and hashtags (mean 20.39) than vaping-warning posts had (“like” count: median 12; hashtags: mean 7.16).

Conclusions: Instagram is dominated by pro-vaping content, and pro-vaping posts and user accounts seem to have more user engagement than vaping-warning accounts have. These results highlight the importance of regulating e-cigarette posts on social media and the urgency of identifying effective communication content and message delivery methods with the public about the health effects of e-cigarettes to ameliorate the epidemic of vaping in youth.

(*JMIR Public Health Surveill* 2020;6(4):e21963) doi:[10.2196/21963](https://doi.org/10.2196/21963)

KEYWORDS

electronic cigarettes; infodemiology; Instagram; user engagement; exploratory; smoking; e-cig; social media; vape; vaping; risk; public health

Introduction

Background

Since the invention of electronic cigarettes (e-cigarettes) in 2003, e-cigarette use (vaping) has increased rapidly worldwide [1]. E-cigarettes have now become the most popular tobacco product among youth in the United States [2]. In the United States, nationwide, the percentages of middle school and high school students who use e-cigarettes increased from 0.6% and 1.5%, respectively, in 2011 to 10.5% and 27.5%, respectively, in 2019 [3,4]. While the long-term effects of vaping on health are not known, multiple studies have demonstrated that components in e-cigarette aerosols may cause severe health problems, including respiratory disorders, cardiovascular diseases, mental health problems, and possibly cancer [5-11]. In addition, nicotine, contained in e-cigarettes, can harm brain function and increase the risk of addiction to other substances [12].

“The science of distribution and determinants of information in an electronic medium, specifically the Internet, or in a population, with the ultimate aim to inform public health and public policy” is defined as infodemiology [13,14]. Analyzing how people communicate and share health-related information on the internet can provide valuable insights into population behavior [14]. Social media platforms, which have been widely used by e-cigarette companies and vape stores for marketing and promoting the sale of their products [15-17], are currently very popular in the United States. Online advertisements from e-cigarette companies and vape stores claim that e-cigarettes have multiple benefits, such as having smoking cessation functions, being more economical than smoking, being healthier than tobacco, and having multiple flavors as choices [18-20]. Studies showed that the exposure to prosubstance-related social media is related to higher substance consumption rates among young people [21,22]. Pokhrel et al [23] demonstrated the association between social media e-cigarette exposure and e-cigarette use beliefs and behavior. Furthermore, initial e-cigarette use has been found to be associated with subsequent cigarette smoking in youth [24-26].

Exposure to the visual imagery of vaping has been shown to act as a conditioned cue to evoke the desire for regular cigarette and e-cigarette use [27]. Instagram, one of the most popular social media platforms, has been regularly used by more than half of US youth and young adults [28,29]. Instagram provides a platform for individuals to upload pictures and videos using hashtags as keywords. Keyword searches allow people to explore the images linked to the hashtags, and therefore, interact with the user-generated content [16]. E-cigarette content is popular on Instagram, and advertising companies characterize e-cigarettes as novel devices [16,30,31]. While the e-cigarette-related posts on Instagram are dominated by vaping-promoting images, there is another voice claiming that vaping is potentially harmful. In 2014, the US Food and Drug Administration (FDA) proposed a deeming rule to regulate tobacco products, which included e-cigarettes [32]. In 2018, the FDA launched a comprehensive campaign in high schools and on social media, including Instagram, to warn youth about the

potential risks of using e-cigarettes [33]. Although the FDA has developed various policies to regulate e-cigarettes and warn young people about potential health risks of e-cigarette use [32,33], the percentage of middle school and high school students who are e-cigarette users has been increasing [3,4].

Objective

This study aimed to investigate current vaping-related content on Instagram by comparing user account activities and user engagement between pro-vaping and vaping-warning groups to improve public health awareness, and more importantly, to identify effective ways for future communication about the harm of e-cigarette use.

Methods

Hashtags on Instagram

We started with 2 groups of root keywords: vaping-related keywords and negative-root keywords. After reviewing hundreds of vaping-related Instagram posts and their hashtags, we determined the list of root vaping-related keywords. These keywords covered the essential pro-vaping products or behaviors on Instagram, such as *vape*, *vaping*, *ecig*, *juul*, *eliquid*, and *ejuice*. The negative-root keywords included *quit*, *stop*, *no*, *anti*, *bad*, *danger*, *against*, and *end*. The combinations of negative-root keywords and root vaping-related keywords created a new group of vaping-warning keywords (eg, *antivaping*, *endvape*). Each keyword was input into the search bar on Instagram, which showed a list of hashtags that were derived from that keyword, as well as the total number of posts that used the hashtag. In this way, the final list of pro-vaping hashtags and vaping-warning hashtags were generated and ranked by their total number of posts by October 19, 2019. Due to a significant imbalance in the numbers of hashtags as well as in the numbers of posts for each hashtag between the 2 groups, different cut-points were used to collect the pro-vaping (number of posts ≥ 3000) and vaping-warning (number of posts ≥ 3) hashtags. Popular hashtags from each group are presented in [Multimedia Appendix 1](#).

Data Collection

The posts were collected through Instagram’s application programming interface, using popular hashtags from both pro-vaping hashtag (*#ecig*, *#ecigarette*, *#ecigarettes*, *#ecigs*, *#ejuice*, *#electroniccigarette*, *#eliquid*, *#juul*, *#vape*, *#vapefam*, *#vapenation*, *#vapeon*, *#vapercon*, *#vapers*, *#vapes*, *#vaping*) and vaping-warning hashtag (*#novape*, *#novaping*, *#stopvaping*, *#dontvape*, *#antivaping*, *#quitvaping*, *#antivape*, *#stopjuuling*, *#dontvapeonthepizza*, *#escapethevape*) groups. Pro-vaping posts and vaping-warning posts were collected on November 18, 2019. Most posts used multiple hashtags, which resulted in duplicated posts when we collected data. Duplicated posts were excluded using the Instagram user ID and posting date. Random samples of posts and user accounts were selected for hand coding other features, including image type, attitude, and account type.

Data Coding and Analysis

We first reviewed hundreds of posts and modified the coding scheme from a previous study [31] to develop our codebook. The codebook contained both metadata and other features that we created. Simple random sampling is a commonly used sample selection method that ensures the samples are representative of the population and that the statistics obtained from the sample are unbiased estimates of the population parameters [34]. Therefore, 200 posts each were randomly selected from both pro-vaping and vaping-warning data sets for hand coding using the simple random sampling method. This procedure was repeated twice to ensure that the 200 samples were representative of the whole data set. The proportions of each account type in each group were compared between 2 repeat samplings using the two-tailed chi-square test with a 5% level of significance.

For accounts, all the posts in each data set were grouped by user ID. Random user account samples (200 accounts) were selected from the Instagram account user IDs in each data set for hand coding. To increase the accuracy, the codebook was further revised during hand coding: All hand coding was performed independently by 2 authors, and the differences were resolved by discussions. The 2 reviewers' agreement on classifying posts was very high (97.5%).

Instagram posts and user accounts were classified into pro-vaping (eg, promoting the use of e-cigarette-related products), vaping warning (eg, disagreeing with vaping behavior or emphasizing the potential health risks of vaping), neutral to vaping (eg, describing a fact related to e-cigarettes without clearly expressing an opinion), or not related to vaping (eg, having both image and caption not related to e-cigarettes, but using e-cigarette-related hashtags to target different groups of people). The visual and textual content were considered together to determine the attitude of each Instagram post [35]. The user account attitude was determined by browsing all the posts related to e-cigarettes on the user's account page.

Type of image was categorized as (1) advertisement, for example, a picture displaying discount information of e-cigarette products; (2) catchphrase, for example, a picture emphasizing slogans such as "don't juul in school" or "athletes don't vape"; (3) product display, for example, a professional photo of an e-liquid container or e-cigarette device; (4) educational, for example, images that stated research results or facts about e-cigarettes; (5) events, for example, an image showing people attending a presentation or workshop related to e-cigarettes; (6) memes, for example, a picture created to deliver an e-cigarette-related message while being comedic; (7) news/notice, for example, image of a newspaper story or screen capture from TV of e-cigarette-related events; (8) vaping, for example, a person exhaling an aerosol; and (9) other, which included those not falling into any previously defined category. The image types were compared between the pro-vaping and vaping-warning posts.

Type of user account included (1) pro-vaping community, for example, a website claiming that e-cigarettes could benefit people; (2) personal, users who didn't have an either commercial or professional affiliation; (3) sponsored vapor, an user who was sponsored by certain e-cigarette brands or stores and posted pictures of their products on Instagram; (4) store, for example, a grocery store selling e-cigarette products; (5) vaping store, a store that only sells e-cigarette products; (6) community, for example, a county uploading all local news, including e-cigarette-related information; (7) vaping-warning community, for example, a parent organization that is specifically against kids vaping; (8) business organization, for example, a law firm posting vaping-warning pictures to receive more vaping illness cases; and (9) influencer, users who have established credibility and a large number of followers.

The distribution of the follower count and the media count for each Instagram user account and the "like" count of each post were calculated, and the median values were compared between the pro-vaping group and the vaping-warning group using a two-tailed permutation test with a 5% level of significance. The mean number of hashtags and most frequently used hashtags in the 2 groups were calculated and compared using two-tailed two-sample *t* tests with a 5% level of significance.

Results

Characteristics of Pro-Vaping and Vaping-Warning Instagram Posts

While many pro-vaping hashtags had tens of millions of posts, the most popular vaping-warning hashtags in our list only had thousands of posts (Multimedia Appendix 1). Using pro-vaping and vaping-warning hashtags, we collected 41,412 unique pro-vaping posts and 1539 unique vaping-warning posts, of which, 200 pro-vaping and 200 vaping-warning posts were randomly selected for hand coding.

Figure 1 displays the distribution of "like" counts of pro-vaping posts and vaping-warning posts. Pro-vaping posts (median 22) had more "likes" ($P < .001$) than vaping-warning posts had (median 12), although there were large within-group variations. The frequency distributions of image types were significantly different between pro-vaping posts and vaping-warning posts ($P < .001$) (Figure 2). Of the pro-vaping posts, product display-type images were the most common (163/200, 81.5%), followed by advertisement (23/200, 11.5%) and vaping activity (8/200, 4%). Among the vaping-warning posts, the most popular image type was educational (95/200, 47.5%), followed by news/notice (21/200, 10.5%), catchphrase (16/200, 8%), events (15/200, 7.5%), and memes (15/200, 7.5%). These analyses were repeated by randomly selecting another 200 pro-vaping and 200 vaping-warning posts. The percentages of image types in each group were consistent between the 2 repeat samplings (Multimedia Appendix 2 and Multimedia Appendix 3).

Figure 1. Number of "likes" for pro-vaping and vaping-warning posts.

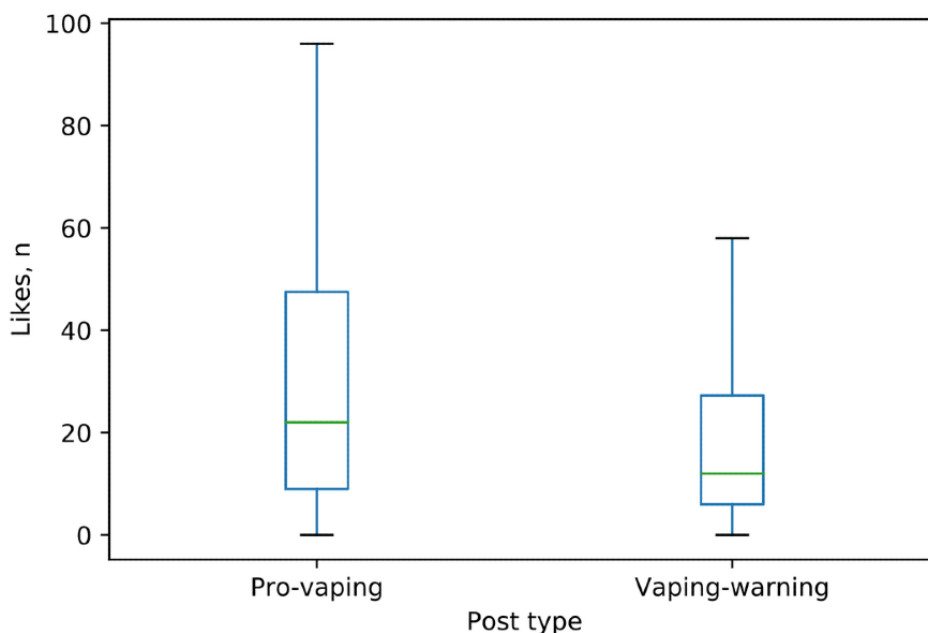
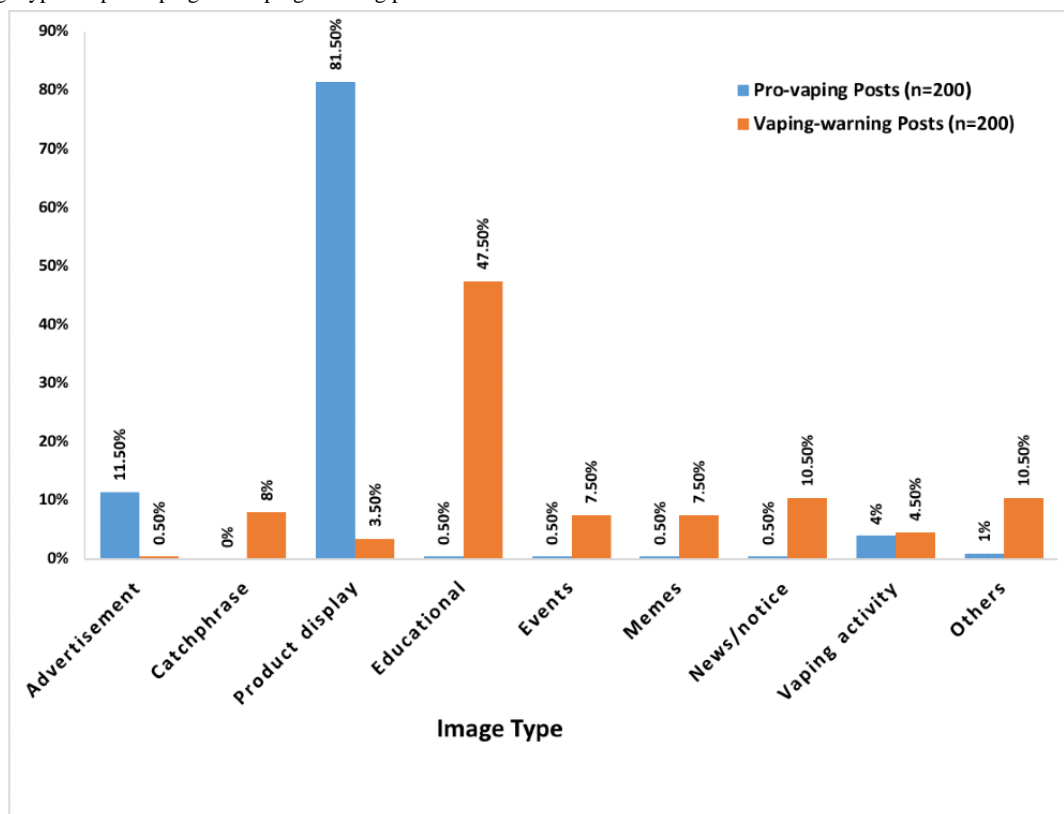


Figure 2. Image types of pro-vaping and vaping-warning posts.



The number of hashtags for pro-vaping posts (mean 20) was significantly higher ($P < .001$) than that for vaping-warning posts (mean 7) (Multimedia Appendix 4). As one of the essential metrics on social media, the top 20 hashtags used for each group of posts are shown in Table 1. Each hashtag used in the

pro-vaping posts was more frequently used compared to those used in the vaping-warning posts, which further demonstrated that pro-vaping posts generally used more hashtags. Some hashtags, such as #vaping and #vape, were widely used in both pro-vaping and vaping-warning posts.

Table 1. Top 20 hashtags in 200 pro-vaping and 200 vaping-warning posts.

Hashtags	Posts ^a , n (%)
Pro-vaping	
#vape	116 (58.0)
#vapelife	85 (42.5)
#vapecommunity	78 (39.0)
#vapenation	76 (38.0)
#vapeon	74 (37.0)
#vaping	69 (34.5)
#vapeporn	68 (34.0)
#vapefam	68 (34.0)
#vapers	67 (33.5)
#eliquid	59 (29.5)
#vapedaily	55 (27.5)
#vapelyfe	51 (25.5)
#ecig	50 (25.0)
#vapestagram	49 (24.5)
#vapor	46 (23.0)
#ejuice	44 (22.0)
#vapeshop	43 (21.5)
#instavape	38 (19.0)
#vapelove	37 (18.5)
Vaping-warning	
#vaping	40 (20.0)
#vape	35 (17.5)
#stopvaping	29 (14.5)
#health	19 (9.5)
#dontvape	17 (8.5)
#juul	15 (7.5)
#nojuul	15 (7.5)
#novaping	14 (7.0)
#escapethevape	13 (6.5)
#vapingdangers	13 (6.5)
#tobaccofree	13 (6.5)
#teenvaping	12 (6.0)
#smokefree	12 (6.0)
#novapingcampaign	10 (5.0)
#breathealoha	10 (5.0)
#novape	10 (5.0)
#antivape	10 (5.0)
#endyouthvaping	9 (4.5)
#stopthevape	9 (4.5)

^aHashtags could be found in more than one post.

Characteristics of Pro-Vaping and Vaping-Warning Instagram User Accounts

The 41,412 pro-vaping posts identified in this study were posted by 18,074 unique Instagram user accounts, while the 1539 vaping-warning posts were posted by 712 unique user accounts. Out of the 200 randomly selected accounts from the pro-vaping group data set, 189 accounts (94.5%) were identified as

pro-vaping user accounts. Out of the 200 randomly selected accounts in the vaping-warning data set, most were vaping-warning user accounts (155/200, 77.5%). Compared with those of the vaping-warning accounts (median 191, pro-vaping user accounts (median 850) had more followers ($P < .001$; Figure 3). The media (posts) count of the pro-vaping user accounts (median 232) was higher ($P < .001$) than that of the vaping-warning user accounts (median 92; Figure 4).

Figure 3. Follower counts of pro-vaping and vaping-warning Instagram accounts.

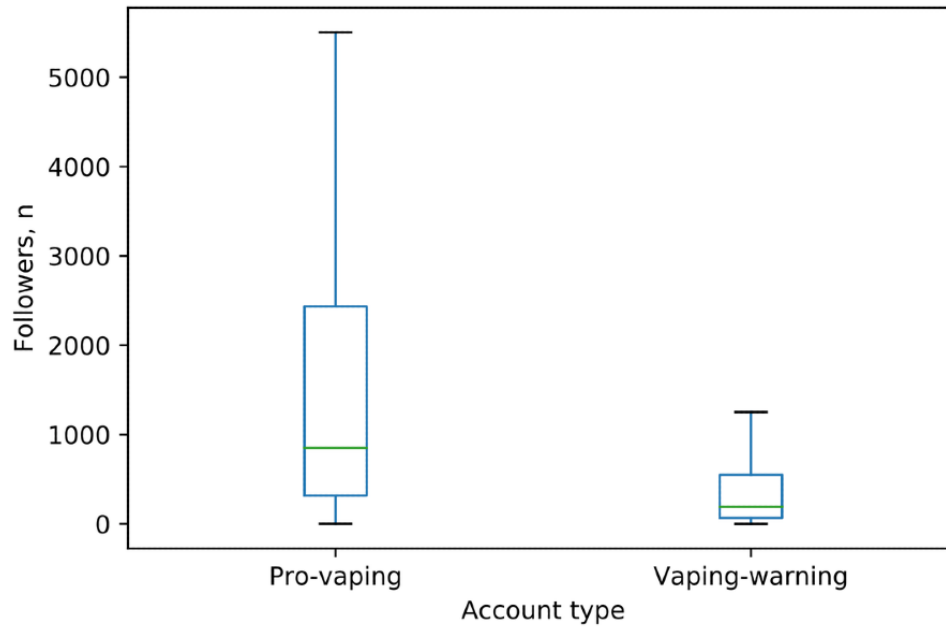


Figure 4. Media counts of pro-vaping and vaping-warning Instagram accounts.

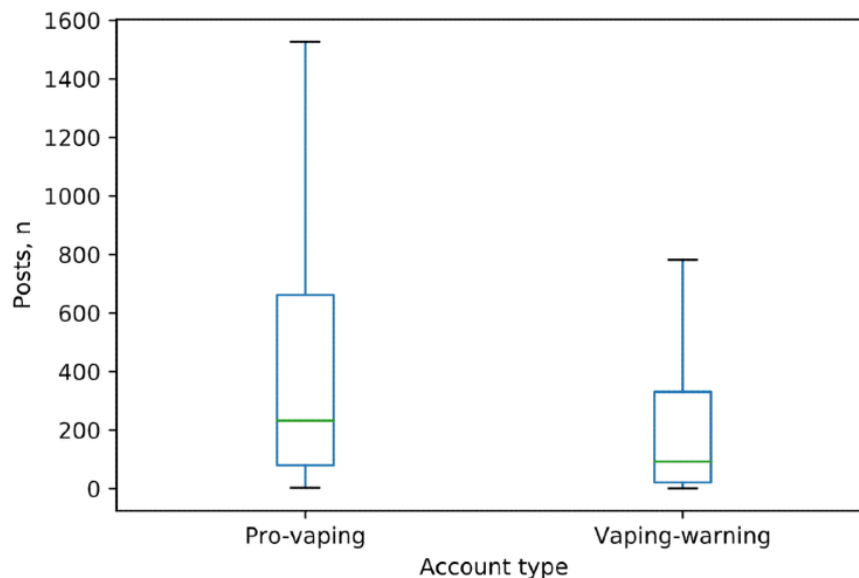


Table 2 summarizes the account types of pro-vaping accounts as well as pro-vaping posts collected from those user accounts. The most popular pro-vaping user account type was vaping store (110, 58.1%), which accounted for half of the posts (231/452, 51.1%); 18% of user accounts were personal (34/189),

and 15.9% were sponsored vapor (30/189), which contributed 15.3% (69/452) and 10.3% (49/452) of posts, respectively. Only 3.2% (6/189) user accounts were pro-vaping communities, and only 4.8% (9/189) were stores; however, 20.6% of the pro-vaping posts (93/452) were from the store user accounts.

Table 2. Types of pro-vaping Instagram user accounts.

Account types	Accounts, n (%)	Pro-vaping posts, n (%)	Posts/account, mean
Total	189 (100)	452 (100)	—^a
Pro-vaping community	6 (3.2)	10 (2.2)	1.67
Personal	34 (18)	69 (15.3)	2.03
Sponsored vapor	30 (15.9)	49 (10.8)	1.63
Store	9 (4.8)	93 (20.6)	10.33
Vaping store	110 (58.1)	231 (51.1)	2.1

^aNot reported.

Type and composition of vaping-warning user accounts and their posts is summarized in [Table 3](#). The top 3 vaping-warning user account types were personal (79/155, 51%), vaping-warning

community (37/155, 23.9%), and community (35/155, 22.6%), which posted 34% (99/291), 46.8% (136/291) and 17.9% (52/291) of the vaping-warning posts, respectively.

Table 3. The account types of the vaping-warning Instagram user accounts.

Account types	Accounts, n (%)	Vaping-warning posts, n (%)	Posts/account, mean
Total	155 (100)	291 (100)	—^a
Community	35 (22.6)	52 (17.9)	1.49
Antivaping community	37 (23.9)	136 (46.8)	3.68
Personal	79 (51)	99 (34)	1.25
Influencer	1 (0.6)	1 (0.3)	1
Business organization	3 (1.9)	3 (1)	1

^aNot reported.

Discussion

Principal Findings

In this study, we showed that e-cigarette-related content on Instagram was highly imbalanced and dominated by pro-vaping posts. Most pro-vaping images were product display images, and vaping store was the most common user account type among pro-vaping user accounts. In contrast, the most popular image type of the vaping-warning posts was educational, and personal was the top vaping-warning account type among vaping-warning user accounts. In addition, pro-vaping user accounts had more followers and posts than those of vaping-warning users, and pro-vaping posts had more “likes” and hashtags than those of vaping-warning posts.

Comparison With Prior Work

Vaping-related studies on social media mainly rely upon hashtags for collecting data. While some have directly used a few frequently appearing hashtags [16,17], others used hashtags by determining several root-term hashtags and finding co-occurring hashtags [30,31,36]. However, using these 2 methods, vaping-warning hashtags may be completely missing due to nonfrequent posting. Here, we developed a way to analyze the pro-vaping and vaping-warning hashtags on Instagram. The numbers of hashtags as well as the numbers of posts for each hashtag between the 2 groups were highly imbalanced ([Multimedia Appendix 1](#)). Even with different cut-points, the pro-vaping group still had more hashtags than vaping-warning group had. Considering the hashtags were used

by e-cigarette companies as a strategy to promote their products [37], further study on how to efficiently use hashtags to improve the impact of vaping-warning campaigns is required.

On Instagram, each pro-vaping hashtag was found in more than 4000 posts, while each vaping-warning hashtag was only found in less than 100 posts. Further hand coding showed the majority of the posts and user accounts based on the pro-vaping hashtags were indeed pro-vaping. These results demonstrated that social media is dominated by vaping-promotion information, consistent with the findings of previous reports [38,39]. These analyses highlight the need for active public health engagement in communicating the harm of vaping on Instagram.

[Figure 2](#) showed that the image types of pro-vaping posts were relatively consistent, while the image types of vaping-warning posts varied. [Table 2](#) and [Table 3](#) indicated different frequencies of posts by account types. Further analysis will be necessary to identify the vaping-warning account types and image types that have more impact in communication with the public, in order to help improve the efficiency in conveying the health risks of vaping to the public.

In this study, we showed that pro-vaping Instagram posts had a higher median “like” counts than those of vaping-warning posts ([Figure 1](#)). However, a person who “likes” a post does not necessarily support e-cigarette products or vaping-related content in the post. Most product-display images were professional pictures from vaping stores or well-designed pictures from sponsored photographers or models. Someone may “like” the post because of the design of the pictures (such

as a beautiful view or a seductive model in the picture). In addition, our results showed that the number of followers and number of hashtags in the pro-vaping group were higher than those of the vaping-warning group. Followers [40] and hashtags [37] have been shown to be essential metrics on social media, which may help with the spread of information and increase the chance of getting “likes.” Although “likes” could be for multiple reasons, the high “like” count is always perceived as the behavior or content in the images being appropriate and accepted by society [41], which may cause more youth to start using e-cigarettes. Therefore, the policies for regulating the pro-vaping posts and approaches for improving user engagement with vaping-warning posts are in high demand.

Linnea et al [30] identified some hashtag communities (eg, *#vapefam*, *#vapecommunity*) used in the pro-vaping Instagram posts. Those users reinforced their identities through a folksonomy process [35,42]. We showed that there were some hashtag communities in the vaping-warning group (eg, *#athletesdontvape*, *#parentsagainstvaping*). The self-identification within those communities may help spread warnings of potential health risks in the vaping-warning posts. Therefore, more of such folksonomy terms should be generated for different groups of people (eg, *#studentsdontvape* for middle and high school students, *#youthdontvape* for the youth) and adopted by more vaping-warning posts to effectively deliver vaping-warning information to diverse populations. Other than pro-vaping and vaping-warning hashtag communities, there were some hashtags widely used by both pro-vaping and vaping-warning posts. For example, *#vape* and *#vaping* were the top hashtags in both pro-vaping and vaping-warning groups, while most posts using these hashtags were pro-vaping. This phenomenon was mainly due to the fact that social media platforms are currently dominated by vaping brands. In addition, the high frequency of hashtags used in pro-vaping posts could

contribute to this result. However, as more vaping-warning campaigns are launched, we should consider these vaping terms (eg, *#vape*, *#vaping*, *#ecig*, *#juul*) as general vaping-related hashtags without attitudes.

Limitations

This study had several limitations. First, some popular hashtags are generated by describing vaping (eg, *#cloudchasing*, *#cloudchaser*, *#cloudchasers*) or vaping-warning (eg, *#choosecleanair*) content other than those directly derived from our root keywords and were missing in our analyses. Second, our data were collected using Instagram’s proprietary search algorithms, which may introduce inevitable and nontransparent biases to the investigation. Data-driven approaches will be used in future work. Third, we did not know the demographic information of Instagram users. Fourth, due to the low frequency of vaping-warning Instagram posts, we collected less than 2000 unique vaping-warning posts, while there were more than 40,000 pro-vaping posts collected. This imbalance may introduce some biases into our analysis. In the future, more vaping-warning posts will be collected to get a more balanced data set for detailed studies to identify critical features that have the potential to increase the impact of vaping-warning campaigns.

Conclusions

This study reported and characterized the current imbalance in pro-vaping and vaping-warning content on Instagram, showing fewer posts and less user engagement of vaping-warning information. Our results highlighted the urgency to regulate social media on e-cigarette-related content. Vaping-warning posts could potentially use more hashtags or a better image designs for more user engagement and to deliver precise and proper e-cigarette-related information to the public, especially youth.

Acknowledgments

Research reported in this publication was supported by the National Cancer Institute of the National Institutes of Health and the US Food and Drug Administration Center for Tobacco Products (award number U54CA228110). The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health or the US Food and Drug Administration.

Authors' Contributions

YG, ZX, and DL conceived and designed the study. YG and LS analyzed the data. YG wrote the manuscript. YG, CX, ZX, and DL assisted with interpretation of analyses and edited the manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Pro-vaping and vaping-warning hashtags.

[[XLSX File \(Microsoft Excel File\), 16 KB - publichealth_v6i4e21963_app1.xlsx](#)]

Multimedia Appendix 2

Comparison of the proportions of pro-vaping image types between 2 repeats.

[[PNG File , 82 KB - publichealth_v6i4e21963_app2.png](#)]

Multimedia Appendix 3

Comparison of the proportions of vaping-warning image types between 2 repeats.

[PNG File , 85 KB - [publichealth_v6i4e21963_app3.png](#)]

Multimedia Appendix 4

Average number of hashtags used by the pro-vaping and vaping-warning groups.

[PNG File , 23 KB - [publichealth_v6i4e21963_app4.png](#)]

References

1. WHO global report on trends in prevalence of tobacco smoking 2000-2025 - Second edition. World Health Organization. Geneva; 2018. URL: <https://apps.who.int/iris/bitstream/handle/10665/272694/9789241514170-eng.pdf?ua=1> [accessed 2020-10-26]
2. Gentzke AS, Creamer M, Cullen KA, Ambrose BK, Willis G, Jamal A, et al. Vital signs: tobacco product use among middle and high school students - United States, 2011-2018. *MMWR Morb Mortal Wkly Rep* 2019 Feb 15;68(6):157-164 [FREE Full text] [doi: [10.15585/mmwr.mm6806e1](https://doi.org/10.15585/mmwr.mm6806e1)] [Medline: [30763302](https://pubmed.ncbi.nlm.nih.gov/30763302/)]
3. Wang TW, Gentzke AS, Creamer MR, Cullen KA, Holder-Hayes E, Sawdey MD, et al. Tobacco product use and associated factors among middle and high school students - United States, 2019. *MMWR Surveill Summ* 2019 Nov 06;68(12):1-22. [doi: [10.15585/mmwr.ss6812a1](https://doi.org/10.15585/mmwr.ss6812a1)] [Medline: [31805035](https://pubmed.ncbi.nlm.nih.gov/31805035/)]
4. Cullen KA, Gentzke AS, Sawdey MD, Chang JT, Anic GM, Wang TW, et al. e-cigarette use among youth in the United States, 2019. *JAMA* 2019 Nov 05;322(21):2095 [FREE Full text] [doi: [10.1001/jama.2019.18387](https://doi.org/10.1001/jama.2019.18387)] [Medline: [31688912](https://pubmed.ncbi.nlm.nih.gov/31688912/)]
5. McConnell R, Barrington-Trimis JL, Wang K, Urman R, Hong H, Unger J, et al. Electronic cigarette use and respiratory symptoms in adolescents. *Am J Respir Crit Care Med* 2017 Apr 15;195(8):1043-1049 [FREE Full text] [doi: [10.1164/rccm.201604-0804OC](https://doi.org/10.1164/rccm.201604-0804OC)] [Medline: [27806211](https://pubmed.ncbi.nlm.nih.gov/27806211/)]
6. Sleiman M, Logue JM, Montesinos VN, Russell ML, Litter MI, Gundel LA, et al. Emissions from electronic cigarettes: key parameters affecting the release of harmful chemicals. *Environ Sci Technol* 2016 Sep 06;50(17):9644-9651. [doi: [10.1021/acs.est.6b01741](https://doi.org/10.1021/acs.est.6b01741)] [Medline: [27461870](https://pubmed.ncbi.nlm.nih.gov/27461870/)]
7. Rubenstein DA, Hom S, Ghebrehiwet B, Yin W. Tobacco and e-cigarette products initiate Kupffer cell inflammatory responses. *Mol Immunol* 2015 Oct;67(2 Pt B):652-660. [doi: [10.1016/j.molimm.2015.05.020](https://doi.org/10.1016/j.molimm.2015.05.020)] [Medline: [26072673](https://pubmed.ncbi.nlm.nih.gov/26072673/)]
8. MacDonald A, Middlekauff HR. Electronic cigarettes and cardiovascular health: what do we know so far? *Vasc Health Risk Manag* 2019;15:159-174 [FREE Full text] [doi: [10.2147/VHRM.S175970](https://doi.org/10.2147/VHRM.S175970)] [Medline: [31417268](https://pubmed.ncbi.nlm.nih.gov/31417268/)]
9. Wills TA, Pagano I, Williams RJ, Tam EK. E-cigarette use and respiratory disorder in an adult sample. *Drug Alcohol Depend* 2019 Jan 01;194:363-370 [FREE Full text] [doi: [10.1016/j.drugalcdep.2018.10.004](https://doi.org/10.1016/j.drugalcdep.2018.10.004)] [Medline: [30472577](https://pubmed.ncbi.nlm.nih.gov/30472577/)]
10. Obisesan OH, Mirbolouk M, Osei AD, Orimoloye OA, Uddin SMI, Dzaye O, et al. Association between e-cigarette use and depression in the behavioral risk factor surveillance system, 2016-2017. *JAMA Netw Open* 2019 Dec 02;2(12):e1916800 [FREE Full text] [doi: [10.1001/jamanetworkopen.2019.16800](https://doi.org/10.1001/jamanetworkopen.2019.16800)] [Medline: [31800073](https://pubmed.ncbi.nlm.nih.gov/31800073/)]
11. Tang MS, Wu XR, Lee HW, Xia Y, Deng FM, Moreira AL, et al. Electronic-cigarette smoke induces lung adenocarcinoma and bladder urothelial hyperplasia in mice. *Proc Natl Acad Sci U S A* 2019 Oct 22;116(43):21727-21731. [doi: [10.1073/pnas.1911321116](https://doi.org/10.1073/pnas.1911321116)] [Medline: [31591243](https://pubmed.ncbi.nlm.nih.gov/31591243/)]
12. US Dept of Health and Human Services, Centers for Disease Control and Prevention, National Center for Chronic Disease Prevention and Health Promotion. E-cigarette Use Among Youth and Young Adults: A Report of the Surgeon General. Office on Smoking and Health. Atlanta, GA; 2016. URL: https://e-cigarettes.surgeongeneral.gov/documents/2016_SGR_Full_Report_non-508.pdf [accessed 2020-09-22]
13. Mavragani A. Infodemiology and infoveillance: scoping review. *J Med Internet Res* 2020 Apr 28;22(4):e16206 [FREE Full text] [doi: [10.2196/16206](https://doi.org/10.2196/16206)] [Medline: [32310818](https://pubmed.ncbi.nlm.nih.gov/32310818/)]
14. Eysenbach G. Infodemiology and infoveillance: framework for an emerging set of public health informatics methods to analyze search, communication and publication behavior on the Internet. *J Med Internet Res* 2009 Mar 27;11(1):e11 [FREE Full text] [doi: [10.2196/jmir.1157](https://doi.org/10.2196/jmir.1157)] [Medline: [19329408](https://pubmed.ncbi.nlm.nih.gov/19329408/)]
15. McCausland K, Maycock B, Leaver T, Jancey J. The messages presented in electronic cigarette-related social media promotions and discussion: scoping review. *J Med Internet Res* 2019 Feb 05;21(2):e11953 [FREE Full text] [doi: [10.2196/11953](https://doi.org/10.2196/11953)] [Medline: [30720440](https://pubmed.ncbi.nlm.nih.gov/30720440/)]
16. Lee A, Hart J, Sears C, Walker K, Siu A, Smith C. A picture is worth a thousand words: electronic cigarette content on Instagram and Pinterest. *Tob Prev Cessat* 2017 Jul;3 [FREE Full text] [doi: [10.18332/tpc/74709](https://doi.org/10.18332/tpc/74709)] [Medline: [28815224](https://pubmed.ncbi.nlm.nih.gov/28815224/)]
17. Sears C, Walker K, Hart J, Lee A, Siu A, Smith C. Clean, cheap, convenient: promotion of electronic cigarettes on YouTube. *Tob Prev Cessat* 2017 Apr;3 [FREE Full text] [doi: [10.18332/tpc/69393](https://doi.org/10.18332/tpc/69393)] [Medline: [28725876](https://pubmed.ncbi.nlm.nih.gov/28725876/)]
18. Clark EM, Jones CA, Williams JR, Kurti AN, Norotsky MC, Danforth CM, et al. Vaporous marketing: uncovering pervasive electronic cigarette advertisements on Twitter. *PLoS One* 2016;11(7):e0157304 [FREE Full text] [doi: [10.1371/journal.pone.0157304](https://doi.org/10.1371/journal.pone.0157304)] [Medline: [27410031](https://pubmed.ncbi.nlm.nih.gov/27410031/)]

19. Ayers JW, Leas EC, Allem J, Benton A, Dredze M, Althouse BM, et al. Why do people use electronic nicotine delivery systems (electronic cigarettes)? a content analysis of Twitter, 2012-2015. *PLoS One* 2017;12(3):e0170702 [FREE Full text] [doi: [10.1371/journal.pone.0170702](https://doi.org/10.1371/journal.pone.0170702)] [Medline: [28248987](https://pubmed.ncbi.nlm.nih.gov/28248987/)]
20. Zhu S, Sun JY, Bonnevie E, Cummins SE, Gamst A, Yin L, et al. Four hundred and sixty brands of e-cigarettes and counting: implications for product regulation. *Tob Control* 2014 Jul;23 Suppl 3:iii3-iii9. [doi: [10.1136/tobaccocontrol-2014-051670](https://doi.org/10.1136/tobaccocontrol-2014-051670)] [Medline: [24935895](https://pubmed.ncbi.nlm.nih.gov/24935895/)]
21. Carrotte ER, Dietze PM, Wright CJ, Lim MS. Who 'likes' alcohol? young Australians' engagement with alcohol marketing via social media and related alcohol consumption patterns. *Aust N Z J Public Health* 2016 Oct;40(5):474-479. [doi: [10.1111/1753-6405.12572](https://doi.org/10.1111/1753-6405.12572)] [Medline: [27624756](https://pubmed.ncbi.nlm.nih.gov/27624756/)]
22. Hoffman EW, Austin EW, Pinkleton BE, Austin BW. An exploration of the associations of alcohol-related social media use and message interpretation outcomes to problem drinking among college students. *Health Commun* 2017 Jul;32(7):864-871. [doi: [10.1080/10410236.2016.1195677](https://doi.org/10.1080/10410236.2016.1195677)] [Medline: [27421038](https://pubmed.ncbi.nlm.nih.gov/27421038/)]
23. Pokhrel, Fagan P, Herzog TA, Laestadius L, Buente W, Kawamoto CT, et al. Social media e-cigarette exposure and e-cigarette expectancies and use among young adults. *Addict Behav* 2018 Mar;78:51-58 [FREE Full text] [doi: [10.1016/j.addbeh.2017.10.017](https://doi.org/10.1016/j.addbeh.2017.10.017)] [Medline: [29127784](https://pubmed.ncbi.nlm.nih.gov/29127784/)]
24. Soneji S, Barrington-Trimis JL, Wills TA, Leventhal AM, Unger JB, Gibson LA, et al. Association between initial use of e-cigarettes and subsequent cigarette smoking among adolescents and young adults: a systematic review and meta-analysis. *JAMA Pediatr* 2017 Aug 01;171(8):788-797 [FREE Full text] [doi: [10.1001/jamapediatrics.2017.1488](https://doi.org/10.1001/jamapediatrics.2017.1488)] [Medline: [28654986](https://pubmed.ncbi.nlm.nih.gov/28654986/)]
25. Barrington-Trimis JL, Kong G, Leventhal AM, Liu F, Mayer M, Cruz TB, et al. E-cigarette use and subsequent smoking frequency among adolescents. *Pediatrics* 2018 Dec;142(6). [doi: [10.1542/peds.2018-0486](https://doi.org/10.1542/peds.2018-0486)] [Medline: [30397165](https://pubmed.ncbi.nlm.nih.gov/30397165/)]
26. Leventhal AM, Strong DR, Kirkpatrick MG, Unger JB, Sussman S, Riggs NR, et al. Association of electronic cigarette use with initiation of combustible tobacco product smoking in early adolescence. *JAMA* 2015 Aug 18;314(7):700-707 [FREE Full text] [doi: [10.1001/jama.2015.8950](https://doi.org/10.1001/jama.2015.8950)] [Medline: [26284721](https://pubmed.ncbi.nlm.nih.gov/26284721/)]
27. King AC, Smith LJ, Fridberg DJ, Matthews AK, McNamara PJ, Cao D. Exposure to electronic nicotine delivery systems (ENDS) visual imagery increases smoking urge and desire. *Psychol Addict Behav* 2016 Feb;30(1):106-112 [FREE Full text] [doi: [10.1037/adb0000123](https://doi.org/10.1037/adb0000123)] [Medline: [26618797](https://pubmed.ncbi.nlm.nih.gov/26618797/)]
28. Perrin A. Social networking usage. Pew Reserach Center. 2015. URL: <https://www.pewresearch.org/internet/2015/10/08/social-networking-usage-2005-2015/> [accessed 2020-09-22]
29. Clement J. Number of monthly active Instagram users from January 2013 to June 2018 (in millions). Statista. 2019. URL: <https://www.statista.com/statistics/253577/number-of-monthly-active-instagram-users/> [accessed 2020-09-22]
30. Laestadius LI, Wahl MM, Cho YI. #Vapelife: an exploratory study of electronic cigarette use and promotion on Instagram. *Subst Use Misuse* 2016 Oct 14;51(12):1669-1673. [doi: [10.1080/10826084.2016.1188958](https://doi.org/10.1080/10826084.2016.1188958)] [Medline: [27484191](https://pubmed.ncbi.nlm.nih.gov/27484191/)]
31. Chu KH, Allem JP, Cruz TB, Unger JB. Vaping on Instagram: cloud chasing, hand checks and product placement. *Tob Control* 2016 Sep;26(5):575-578 [FREE Full text] [doi: [10.1136/tobaccocontrol-2016-053052](https://doi.org/10.1136/tobaccocontrol-2016-053052)] [Medline: [27660111](https://pubmed.ncbi.nlm.nih.gov/27660111/)]
32. Statements by President Bill Clinton and the US Food and Drug Administration on regulations to restrict the marketing, sale, and distribution of tobacco to children. *Tobacco Control*. 1995 Sep 01. URL: <https://tinyurl.com/yyudma94> [accessed 2020-09-22]
33. FDA launches new, comprehensive campaign to warn kids about the dangers of e-cigarette use as part of agency's Youth Tobacco Prevention Plan, amid evidence of sharply rising use among kids. US Food and Drug Administration. 2018. URL: <https://www.fda.gov/news-events/press-announcements/fda-launches-new-comprehensive-campaign-warn-kids-about-dangers-e-cigarette-use-part-agencys-youth> [accessed 2020-09-22]
34. Setia M. Methodology series module 5: sampling strategies. *Indian J Dermatol* 2016;61(5):505-509 [FREE Full text] [doi: [10.4103/0019-5154.190118](https://doi.org/10.4103/0019-5154.190118)] [Medline: [27688438](https://pubmed.ncbi.nlm.nih.gov/27688438/)]
35. Highfield T, Leaver T. A methodology for mapping Instagram hashtags. *First Monday* 2014 Dec 26;1-11. [doi: [10.5210/fm.v20i1.5563](https://doi.org/10.5210/fm.v20i1.5563)]
36. Huang J, Kornfield R, Emery SL. 100 million views of electronic cigarette YouTube videos and counting: quantification, content evaluation, and engagement levels of videos. *J Med Internet Res* 2016 Mar 18;18(3):e67 [FREE Full text] [doi: [10.2196/jmir.4265](https://doi.org/10.2196/jmir.4265)] [Medline: [26993213](https://pubmed.ncbi.nlm.nih.gov/26993213/)]
37. van der Tempel J, Noormohamed A, Schwartz R, Norman C, Malas M, Zawertailo L. Vape, quit, tweet? Electronic cigarettes and smoking cessation on Twitter. *Int J Public Health* 2016 Mar;61(2):249-256. [doi: [10.1007/s00038-016-0791-2](https://doi.org/10.1007/s00038-016-0791-2)] [Medline: [26841895](https://pubmed.ncbi.nlm.nih.gov/26841895/)]
38. Emery SL, Vera L, Huang J, Szczypka G. Wanna know about vaping? Patterns of message exposure, seeking and sharing information about e-cigarettes across media platforms. *Tob Control* 2014 Jul;23 Suppl 3:iii17-iii25. [doi: [10.1136/tobaccocontrol-2014-051648](https://doi.org/10.1136/tobaccocontrol-2014-051648)] [Medline: [24935893](https://pubmed.ncbi.nlm.nih.gov/24935893/)]
39. Allem J, Ferrara E, Uppu SP, Cruz TB, Unger JB. E-cigarette surveillance with social media data: social bots, emerging topics, and trends. *JMIR Public Health Surveill* 2017 Dec 20;3(4):e98 [FREE Full text] [doi: [10.2196/publichealth.8641](https://doi.org/10.2196/publichealth.8641)] [Medline: [29263018](https://pubmed.ncbi.nlm.nih.gov/29263018/)]

40. Brownlee M. Top 10 Instagram analytics metrics you need to measure. Kilpfolio. URL: <https://www.klipfolio.com/blog/10-essential-instagram-analytics-metrics> [accessed 2020-09-22]
41. Sherman LE, Greenfield PM, Hernandez LM, Dapretto M. Peer influence via instagram: effects on brain and behavior in adolescence and young adulthood. *Child Dev* 2018 Jan;89(1):37-47 [FREE Full text] [doi: [10.1111/cdev.12838](https://doi.org/10.1111/cdev.12838)] [Medline: [28612930](https://pubmed.ncbi.nlm.nih.gov/28612930/)]
42. Highfield T, Leaver T. A methodology for mapping Instagram hashtags. *First Monday* 2014 Dec 26;20(1). [doi: [10.5210/fm.v20i1.5563](https://doi.org/10.5210/fm.v20i1.5563)]

Abbreviations

e-cigarette: electronic cigarette

FDA: US Food and Drug Administration

Edited by G Eysenbach; submitted 30.06.20; peer-reviewed by T Freeman, A Mavragani; comments to author 03.08.20; revised version received 23.09.20; accepted 24.09.20; published 05.11.20.

Please cite as:

Gao Y, Xie Z, Sun L, Xu C, Li D

Electronic Cigarette-Related Contents on Instagram: Observational Study and Exploratory Analysis

JMIR Public Health Surveill 2020;6(4):e21963

URL: <http://publichealth.jmir.org/2020/4/e21963/>

doi: [10.2196/21963](https://doi.org/10.2196/21963)

PMID: [33151157](https://pubmed.ncbi.nlm.nih.gov/33151157/)

©Yankun Gao, Zidian Xie, Li Sun, Chenliang Xu, Dongmei Li. Originally published in JMIR Public Health and Surveillance (<http://publichealth.jmir.org>), 05.11.2020. This is an open-access article distributed under the terms of the Creative Commons Attribution License (<https://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in JMIR Public Health and Surveillance, is properly cited. The complete bibliographic information, a link to the original publication on <http://publichealth.jmir.org>, as well as this copyright and license information must be included.

Original Paper

Public Response to a Social Media Tobacco Prevention Campaign: Content Analysis

Anuja Majmundar¹, MBA, MA, PhD; NamQuyen Le², MPH; Meghan Bridgid Moran³, PHD; Jennifer B Unger¹, PHD; Katja Reuter¹, PhD

¹Department of Preventive Medicine, Keck School of Medicine, University of Southern California, Los Angeles, CA, United States

²Southern California Clinical and Translational Science Institute, Keck School of Medicine, University of Southern California, Los Angeles, CA, United States

³Department of Health, Behavior & Society, Johns Hopkins University Bloomberg School of Public Health, Baltimore, MD, United States

Corresponding Author:

Katja Reuter, PhD

Department of Preventive Medicine

Keck School of Medicine

University of Southern California

2001 N Soto St

Los Angeles, CA, 90032

United States

Phone: 1 (800) 872 2273

Email: katja.reuter@gmail.com

Abstract

Background: Prior research suggests that social media-based public health campaigns are often targeted by countercampaigns.

Objective: Using reactance theory as the theoretical framework, this research characterizes the nature of public response to tobacco prevention messages disseminated via a social media-based campaign. We also examine whether agreement with the prevention messages is associated with comment tone and nature of the contribution to the overall discussion.

Methods: User comments to tobacco prevention messages, posted between April 19, 2017 and July 12, 2017, were extracted from Twitter, Facebook, and Instagram. Two coders categorized comments in terms of tone, agreement with message, nature of contribution, mentions of government agency and regulation, promotional or spam comments, and format of comment. Chi-square analyses tested associations between agreement with the message and tone of the public response and the nature of contributions to the discussions.

Results: Of the 1242 comments received (Twitter: n=1004; Facebook: n=176; Instagram: n=62), many comments used a negative tone (42.75%) and disagreed with the health messages (39.77%), while the majority made healthy contributions to the discussions (84.38%). Only 0.56% of messages mentioned government agencies, and only 0.48% of the comments were antiregulation. Comments employing a positive tone (84.13%) or making healthy contributions (69.11%) were more likely to agree with the campaign messages ($P=0.01$). Comments employing a negative tone (71.25%) or making toxic contributions (36.26%) generally disagreed with the messages ($P=0.01$).

Conclusions: The majority of user comments in response to a tobacco prevention campaign made healthy contributions. Our findings encourage the use of social media to promote dialogue about controversial health topics such as smoking. However, toxicity was characteristic of comments that disagreed with the health messages. Managing negative and toxic comments on social media is a crucial issue for social media-based tobacco prevention campaigns to consider.

(*JMIR Public Health Surveill* 2020;6(4):e20649) doi:[10.2196/20649](https://doi.org/10.2196/20649)

KEYWORDS

social media; health campaign; tobacco; online; health communication; internet; Twitter; Facebook; Instagram

Introduction

Overview

Protobacco messages outnumber antitobacco messages on social media, which raises concerns about their effects on vulnerable populations such as youth [1-3]. Adolescents who engage with tobacco-related content online are more likely to initiate tobacco use and less likely to support tobacco-related regulations [4-6]. Social media accounts associated with tobacco companies, influencers, tobacco enthusiasts, and automated bots (algorithms that automatically produce content and engage with legitimate human accounts on social media) create and disseminate protobacco information online [7-10]. Although sites such as Facebook, Twitter, Instagram, and Google prohibit tobacco marketing, social media users can still view protobacco information in the form of news articles, discussion forums, posts from tobacco retailers, and brand (paid) and organic (unpaid) posts about tobacco use from peers.

Evidence-based tobacco prevention campaigns could play a crucial role in countering the effects and volume of protobacco messages at scale. However, negative public response to such messages from protobacco individuals posting negative comments can potentially undermine these efforts. Real-time surveillance of online health communication campaigns (eg, analysis of metadata such as likes and shares or qualitative data such as comments and posts), although limited, has highlighted negative public responses to tobacco prevention messages. Recent evidence suggests that public responses and organized protobacco groups create a large volume of organic (unpaid) social media messages that are against tobacco awareness campaigns [11,12]. Allem et al [11] found that a countercampaign to California's "Still Blowing Smoke" campaign, "Not Blowing Smoke," questioned health claims and raised objections to electronic cigarette regulations. In another instance, Chicago's tobacco policy campaign was countered using an "astroturfing" strategy, wherein large numbers of bot-generated countermessages conveyed a false consensus that the public disagreed with the policy [12]. Although such a response to health messages on social media is concerning, it also points to missed opportunities of social media engagement directed towards creating dialogue with vulnerable audiences. Social media yields high reach and elicits engagement and activism from audiences [13,14]. To leverage these opportunities, it is crucial to characterize the nature of public responses using a broader sample of tobacco prevention messages and to devise strategies to address negative comments in the future.

Theoretical Framework

The reactance theory provides a useful framework to explain negative public responses to tobacco prevention messages [15-19]. According to reactance theory, when individuals encounter messages that they perceive to threaten their freedom of choice, they experience a motivational state of reactance and act in ways to recover or assert their lost or threatened freedom [20]. Exposure to antitobacco message features may threaten individuals' perceived freedom to smoke and thereby introduce psychological reactance, which results in negative responses

and resistance to such messages. Research also suggests that threat to freedom enhances the attractiveness of the threatened freedom (eg, smoking) and thereby results in higher intentions to exercise that freedom [21]. Tobacco prevention messages, in this context, can potentially threaten multiple free behaviors, such as freedom to smoke and to self-identity as a smoker, and can potentially increase the likelihood of performing unhealthy behaviors [20].

Resistance to tobacco prevention messages may polarize debates on social media [22]. Past evidence suggests that polarized public discussions on social media are marked with one-sided perspectives related to health topics. For instance, Allem et al [11] demonstrated that groups of Twitter users emphasized the potential benefits of electronic cigarettes for cessation but not the potential risks.

Social Media-Based Health Communication

Each social media platform offers unique features for health communication initiatives. As noted in previous research, Facebook can elicit interaction with campaign followers, engagement with health facts and health myths, and the possibility of creating a closed-group communication in the case of sensitive health-related topics such as HIV [23]. Twitter offers instant diffusion of health messages that may lose links with the sources when Twitter users share health messages with their network members, and those network members consequently share the messages with their own networks [24]. Studies evaluating campaigns on Instagram, although limited, suggest that posts with embedded health messages are linked to high perceived message effectiveness [25].

Given the importance of social media campaigns for tobacco education and prevention and the potential for user-generated comments to undermine these efforts, it is critical to understand the nature of such comments. To address this need, this study undertook a content analysis of public response to a semiautomated tobacco prevention campaign on Twitter, Facebook, and Instagram, which was described in detail in a technical paper by Reuter et al [15]. We characterized the nature of these comments along the following 7 dimensions: (1) tone of the comment, (2) nature of contribution, (3) agreement with the prevention message, (4) mentions of government agency, (5) policy/regulation, (6) promotion/spam, and (7) format of comment. We hypothesized that agreement with the prevention messages is significantly associated with the tone of the comment and nature of the contribution.

Methods

Overview of the Campaign

The campaign was live on 3 social media platforms (Twitter, Facebook, and Instagram) from April 19, 2017 to July 12, 2017. Campaign messages comprised of 102 parametrized message templates (defined as messages that fit within the limitations and parameters [eg, character count] of each social media platform) from two government-sponsored health education campaigns on the risks of combustible tobacco products. See [Multimedia Appendix 1](#) for the complete list of parameterized message templates used in this study. We randomized the

message templates within a pool of 226 unique images sourced from government-sponsored campaigns or, in the case of copyright protected campaign images, representative stock images from an online platform, Stocksnap.

A total of 1275 campaign message posts were posted during the study period (Twitter: n=510; Facebook: n=510; Instagram: n=255) as specified in the technical implementation paper published previously [26]. Each campaign message was posted at the most once each month over 85 days. We used a web-based tool (Trial Promoter) developed previously by our team of researchers to disseminate randomly selected messages on each of these platforms.

On seeing the message, users could engage with the post by commenting, sharing, liking, and clicking on the link in the message, which took them to an educational website operational during the campaign period. The website provided more information about the risks of tobacco products, which was based on the government-sponsored health education campaigns. The details of the technology-enhanced implementation of the campaign and examples of messages with images for each platform are depicted in the related technical implementation paper from Reuter et al [15].

We captured responses to all campaigns messages posted during the study period. Approximately 35.68% (569/1595) of the campaign message posts received public comments (after excluding deleted comments or comments from user accounts blocked during the study period). This paper is focused on the analysis of the comments (n=1242) to the campaign. The scope of this research was observational with the intent to characterize the nature of public responses to an antismoking campaign. The intent was not to respond to the public comments, influence the comments, or further engage the audience.

Data

Comments to the campaign messages were extracted from 3 social media platforms (Twitter, Facebook, and Instagram) using an automated tool described previously [15]. The research team collected comments both manually and automatically by logging into the comment moderation interfaces and analytics interfaces provided by each social media platform. Manual collection and automated collections were compared to ensure a complete overview of all responses was captured. The technical tool used in this study supports the following functions: (1) data import, (2) message generation based on randomization techniques, (3) message dissemination, (4) import and analysis of message comments, (5) collection and display of metrics related to message performance, and (6) reporting based on a predetermined data dictionary.

Content Coding

We used a codebook defining coding categories to address the hypothesis. Two independent study team members coded the

comments to the original posts, in terms of 7 coding categories: (1) tone of the comment (positive, negative, or neutral), (2) nature of contribution (toxic, healthy, or unclear/not applicable), (3) agreement with prevention message (agree, disagree, or seek clarification or advice), (4) mentions of government agency (yes or no), (5) policy/regulation (proregulation, antiregulation, neutral-regulation, or not applicable), (6) promotion/spam (yes or no), and (7) format (text only, meme/sticker/emoji/emoticon only, or both). Toxic contributions were defined as “a rude, disrespectful, or unreasonable comment that is likely to make other users leave a discussion” [27], whereas healthy contributions were defined as those using non-toxic language, those that were unclear or for which the classification was not applicable, or those using vague terms or emojis/stickers/emoticons, for which toxicity could not be determined.

As a first step, the coders coded 50 comments and discussed disagreements and results with the principal investigator to refine the initial codebook. Promotional and spam-like comments were identified as an emergent coding category.

To establish intercoder reliability, two coders independently coded 10% of the total sample (N=127). The overall agreement for the themes (94% agreement, $\kappa=0.90$) was substantial. The range of the coding agreement was acceptable and ranged from 92% to 100% ($k=0.85$ to 1). All disagreements were resolved by one of the investigators.



Analysis

Chi-square analysis was used to test associations between the agreement with the message and tone of the response, and with the toxicity of the comments.

Results

The final sample consisted of 1242 comments (Twitter: n=1004; Facebook: n=176; Instagram: n=62). Comments were predominantly text-based (1137/1242, 91.55%) and nonpromotional or nonspam posts (1222/1242, 98.39%). The highest proportion of comments were negative (531/1242, 42.75%), followed by neutral (354/1242, 28.50%), positive comments (126/1242, 10.14%), and other/unclear (231/1242, 18.60%). About 39.77% (494/1242) of the comments disagreed with the health messages, whereas 23.91% (297/1242) of the comments agreed or approved of the health messages. Most of the comments made healthy contributions (1048/1242, 84.38%), while about 12.88% (160/1242) of them were coded as toxic comments. Additionally, there were no mentions of government agencies in 99.44% (1235/1242) of the posts and only 6 of the comments that mentioned government agencies were antiregulation. Please refer to Table 1 for detailed results, including code categories and their corresponding definitions. Example comments were paraphrased to protect the identity of the individuals in this study.

Table 1. Sample characteristics of comments collected from Twitter, Facebook, and Instagram in response to a tobacco prevention campaign.

Category	Number of comments (N=1242), n (%)	Examples ^a
Format		
Text only	1137 (91.55%)	“What do you mean by on average? What is the test subject? Mice?” “Kids may think that smoking makes them looks big with other people that smoke but it doesn't”
Meme/sticker/emoji/emoticon only	36 (2.90%)	 “ ;) ”
Text and meme/sticker/emoji/emoticon	69 (5.56%)	“So are they saying that I should be rolling up a rat poison cigarette? Because if I must then I will  “Amen! :(”
Tone of the comment		
Overall positive tone 126 (10.14%)		
Joyous		“Yeah I heard of that. If you smoke quit for your family and friends. Breathing fresh air is so much better than smoking!”
Hopeful		“15 months and going strong after after 38 yrs.of smoking. Hope this continues!”
Supportive		“Amen that’s why I quit smoking”
Unknown		“Nice. Cheers :)”
Overall negative tone 531 (42.75%)		
Anger		“You're stupid!”
Fear		“That's a lot of people dying from smoking every year. Sooner or later we'll run out of people.”
Sarcasm		“On average? What was your test subject – Mice?”
Disgust		“Ugh Jeez. Smoking is very gross.”
Sadness/despair		“Oh please don't say that--lost my husband when he was 39years old and we had 3 children. He had a horrific painful death”
Unknown		“Smoking and drinking! Why don't you get it morons..How could it possibly go wrong?”
Overall neutral tone 354 (28.50%)		
		“Quit while you can” “No proof”
Other/unclear	231 (18.60%)	“How many lives would be saved with no abortions?”
Agreement		
Agreement (agrees with or approves of the message of the original post)	297 (23.91%)	“Yes, people like me now have COPD. I have never smoked just been around people who have” “Yeah! Sad should have been banned a long time ago!!!!”
Disagreement (engages in disagreement/disbelief/criticism in response to the original post)	494 (39.77%)	“Nope, there's still polluted air btw” “Don't believe this propaganda, not based on facts !”
Clarification and/or advice seeking (posts questions to seek more information or advice).	93 (7.49%)	“Again I ask...how do you recommend we quit quit smoking?” “& it's called 2nd hand smoke?”
Other/unclear	358 (28.82%)	“This is how I will look tomorrow.” “Also with the farm”
Nature of contribution		
Toxic contribution (a rude, disrespectful, or unreasonable comment that is likely to make other users leave a discussion)	160 (12.88%)	“Here’s what I have to say: Haters gonna hate,bitches gonna bitch.” “FUCK YOU”

Category	Number of comments (N=1242), n (%)	Examples ^a
Healthy contribution (comments that did not contain toxic words/language)	1048 (84.38%)	“All smokers read this for sure” “Unfortunately for some, they are so addicted that they were happier than if they had quit . This is een though they would have lived longer, they would have been miserable.”
Unclear/not applicable (comments with vague terms or emojis/stickers/emoticons, for which toxicity could not be determined)	34 (2.74%)	“That reminds me of this (picture of cigarette with smoke attached)”
Mentions of government agency		
Yes (direct or implied mentions of the government and/or government agencies such as FDA ^b /CDC ^c /NIH ^d in the comment)	7 (0.56%)	“How can this be allowed....It's called the FDA” “The FDA stands for ‘FOR DEATH AWAITS,;’”
No (no direct or implied mention of the government and/or government agencies such as FDA/CDC/NIH in the comment)	1235 (99.44%)	“Look, we hate smoking, and am all in favor of the heavy hand of government, but your tweet is a flat out lie. Why not” “#JustBeHonest about it!” “I have a right given to me by our great Bill of rights, to smoke. ,Pre-manufactured foods and the nasty water cause more deaths.”
Policy/regulation^e		
Proregulation (comment references regulation[s] to show support)	1 (0.08%)	“I support this am all in favor of the heavy hand of antismoking government policies”
Antiregulation (comment references regulation[s] to make an antiregulatory statement)	6 (0.48%)	“The FDA puts these things in cigarettes ...They are putting the same poisons in your food and water. But let's just keep blaming tobacco product's. Wake up peoplecancer is a man-made disease It is amazing how the government makes something like a weed illegal a weed that has been here long before any of us.... just amazing” “If no one ate, maybe the cancer rate would go down! If nobody drank, maybe the drunk driving deaths would go down! Maybe you should mind your own business!Just maybe taking the chemicals out of the tobacco that the government (fda) says is okay, maybe cancer would go down!”
Not applicable to regulation (the comment was not about regulation and/or did not reference regulatory bodies to make a pro- or antiregulatory stance)	1235 (99.44%)	“There are nasty things in cigs”
Promotion/spam		
Yes (Comments that promoted either the user's social media or others account, products, or services)	20 (1.61%)	“Follow me fams :)”
No	1222 (98.39%)	N/A ^f

^aExample comments are paraphrased to protect user privacy.

^bFDA: Food and Drug Administration.

^cCDC: Centers for Diseases Control and Prevention.

^dNIH: National Institutes of Health.

^ePro- or antiregulation categories were applicable only when the response mentioned a government agency in the comment.

^fN/A: Not applicable.

Agreement with the message was significantly associated with the tone of the response ($\chi^2 = 1000$, $df=9$; $P=0.01$). Most of the comments that employed a positive tone predominantly agreed with health messages (84.13%, 106/126; eg, “Amen! I agree with this!”), and few expressed disagreement (2.38%, 3/128; eg, “I am not sure I agree but I am willing to listen”) or asked for clarifications (0.79%, 1/128; eg, “Would it be possible to explain how that would work?”). Comments that employed a

negative tone mostly disagreed with prevention messages (69.11%, 367/531; eg, “Stop taking us for a ride!”), followed by those that asked for clarifications (11.11%, 59/531; eg, “Why do you let these companies put all the chemicals in everything?”) or expressed agreement (6.78%, 36/531; eg, “Smoking is indeed a filthy habit”). The comments that used a neutral tone mostly expressed agreement (42.94%, 152/354; eg, “Yes, smoking kills,” followed by those that expressed disagreement (34.75%,

123/354; eg, “This gives me a better reason to smoke”) or sought clarifications (6.21%, 22/354; eg, “How would that happen?”).

Agreement with the message was also significantly associated with the toxicity of the comments ($\chi^2 = 176.23$, $df=6$; $P=0.01$). The majority of the toxic comments disagreed with prevention messages (71.25%, 114/160; eg, “Bullshit! You have no data to support that!”) whereas few agreed with the prevention messages (2.50%, 4/160; eg, “Smoking shit will kill you”) or sought clarifications (12.50%, 20/160; eg, “What the fuck am I looking at?”). Among those comments that made healthy contributions, about one-third of the comments disagreed with the messages (36.26%, 380/1048; eg, “Air pollution causes more deaths than smoking”) followed by ones that agreed with the messages (27.86%, 292/1048; eg, “Amen, that’s why I quit”) or sought clarifications (6.97%, 73/1048; eg, “Any ideas on how to end this epidemic?”).

Discussion

The findings support our hypothesis. Exposure to tobacco prevention health messages on social media stimulated primarily healthy rather than toxic contributions. However, negative and toxic comments mostly disagreed with the health messages. The use of toxic language constitutes incivility online, which is also shown to exacerbate polarity of opinions on social media [28], thus generating more incivility [29]. In general, incivility in online discourse is predominant in social media involving the communication of scientific data or findings [30]. Prevalence of such incivility counteracts public health efforts to educate and inform the public about scientifically proven health risks of tobacco use.

Managing toxic comments on social media is a crucial issue to be addressed for successful health campaigns. Previous research also suggests that public health campaigns on social media may make public health groups a target for counter campaigns with a large volume of anticampaign posts questioning the intent or scientific basis of the messages [11,12]. As such, it is crucial to incorporate comment moderation protocols into tobacco prevention campaigns on social media. This could include automated moderation tools that detect toxic comments to support fast response and moderation [26,31-34], educating the public about conversational techniques that sustain the productivity of online discourses, or deletion of toxic comments and suspension of associated accounts.

There is a need to address symptoms of polarity on social media such as language toxicity or use of negative tone in future health campaigns in the form of counterargumentation or effective moderation of these discussions. Current community standards developed by social media platforms attempt to address this issue by defining benchmarks and policies for online discourse [35,36]. For this health campaign experiment, we blocked 26 users (2.1%; 26 on Facebook, 0 on Twitter, and 0 on Instagram) and deleted 2 of the 1242 comments (0.16%; 2 on Facebook, 0 on Twitter, and 0 on Instagram) that used toxic or particularly offensive language (eg, “Get that stick out of your ass,” “Babies don’t smoke but they may have cancer too,” and “Stop bombarding Facebook with the no smoking bullshit”). Future work may consider a larger sample of posts from blocked users

in terms of the tone, agreement with campaign messages, and nature of contribution. To safeguard free speech online, a moderator could respond to comments that use toxic language and a negative tone using countermessaging strategies to engage those individuals in further dialogue. Emerging evidence suggests that styles of interactive moderation, where moderators request individuals using uncivil or toxic language to use more civil language, differ in their effectiveness [37]. Ziegele et al [37] found that social style of moderation (eg, moderation involving complementing comments informally or creating an informal and pleasant discussion) was associated with decreased incivility. Regulative style of moderation (eg, regulation involving checking for facts complaining about comments, requesting more civil behavior, or pointing to violations of rules) was linked to increased incivility [37]. More work at the intersection of moderation style and counter speech language strategy is needed to address increasing toxicity online. Online health-related campaigns can also benefit from automated detection of incivility, including use of toxic language. Recent efforts to leverage artificial intelligence to identify and address specific behaviors can also play a crucial role in managing the undesirable effects of uncivil discourse [38]. Future interventions can also develop automated alerts for toxic language to inform a moderator that a comment should be looked at.

The reactance theory offers a useful framework to contextualize findings. Most of the negative or toxic comments disagreed with the prevention messages. Toxicity and negative tone, as such, appear to be symptoms of reactance to health messages. Evidence also suggests that reactance to persuasion messages can also lead to source degradation, which is defined as the use of aggression or hostility toward a threatening agent [39]. Thus, minimizing audience reactance to a message is key. Tactics to do this include avoiding overtly freedom-threatening language (eg, telling people they must stop smoking) [40], emphasizing the audience’s freedom to choose [40], avoiding attacks to one’s identity as a smoker [19], and complementing fear-producing messages with an efficacy boosting message (eg, if a message discusses connections between smoking and lung cancer, it should also provide concrete ways for users to stop smoking) [38]. Additionally, because toxic online comments may bias other users against the health message or message source, campaigns can take steps to prevent this from happening. Inoculation theory provides one pathway to accomplish this. This approach involves “inoculating” the audience against possible counterclaims or opposing messages, (eg, warning an audience that “Some argue that vaccines cause autism but science has proven that this is not true”). Allowing the audience to be aware of potential counterattacks to the message can help them better resist said counterattacks and can potentially address reactance and improve health outcomes [41]. Future research can investigate associations between the audience response and inoculation strategies for tobacco prevention campaigns. Developing methods to assess reactivity to health message exposure on social media platforms and examining the nature of online engagement with health messages also offers valuable directions for future work.

Our findings should be viewed in light of several limitations. First, results pertain to public reactions to a specific health-related context of smoking prevention. Future studies may use the automated tool used in this study to examine reactions in other health contexts. Our data is also limited to three social media platforms (Twitter, Instagram, and Facebook) and may not be generalizable to other platforms such as Reddit, YouTube, or SnapChat. Blocking users associated with toxic comments during the campaign may have potentially biased the contribution and tone of the subsequent comments. Future studies may consider examining the effects of toxic comments on subsequent discussions in online health campaigns. In this study, two members of the research team undertook content moderation decisions. We were unable to measure the effectiveness of different moderating strategies such as blocking versus hiding toxic comments. Excluding blocked comments, potentially predominantly toxic, from the analytic sample may have influenced the proportion of toxic comments in our final sample. Moderators also did not respond to any public comments, which may or may not have impacted the trajectory and quality of conversations. Another limitation of this study pertained to treating each comment, including replies to other

users' comments (73/1242, 5.9% of the analytic sample), as an independent unit of observation. While the sample of replies to other users' comments was small, it may have influenced the proportion of coding categories to some extent. We were unable to test associations between some of the categories (eg, "mentions of government agency" and "agreement;" "mentions of government agency" and "toxicity") due to low sample sizes. We were also unable to characterize blocked user comments in terms of their agreement with the campaign message, tone, and nature of contribution due to low sample sizes.

Our research offers insights about the nature of public response to tobacco prevention messages. While revealing concerning trends of toxicity and use of negative tone while expressing disagreements with the prevention messages, our findings also encourage the use of social media to promote dialogue about controversial health topics such as smoking. Future health interventions should develop methods including technology-enhanced techniques to manage toxic user comments and to educate social media users about the harmful effects of toxicity and negative tone in the overall discourse about public health issues.

Acknowledgments

Research reported in this publication was supported by Grant #P50CA180905 from the National Cancer Institute and the Food and Drug Administration (FDA) Center for Tobacco Products. The National Institutes of Health (NIH) or FDA had no role in study design, collection, analysis, and interpretation of data, writing the report, and the decision to submit the report for publication. The content is solely the responsibility of the authors and does not necessarily represent the official views of the NIH or FDA.

The authors would also like to thank Praveen Angyan for his technical support and help with the data extraction as well as Drs. Jon-Patrick Allem and Tess Boley Cruz for their input on the analysis approach.

Conflicts of Interest

MBM serves as a paid expert witness in litigation sponsored by the Public Health Advocacy Institute against RJ Reynolds. This arrangement has been reviewed and approved by the Johns Hopkins University in accordance with its conflict of interest policies. All other authors declare no conflict.

Multimedia Appendix 1

List of parameterized message templates used in the study.

[[DOCX File, 18 KB - publichealth_v6i4e20649_app1.docx](#)]

References

1. Allem J, Ramanujam J, Lerman K, Chu K, Boley CT, Unger JB. Identifying Sentiment of Hookah-Related Posts on Twitter. *JMIR Public Health Surveill* 2017 Oct 18;3(4):e74 [FREE Full text] [doi: [10.2196/publichealth.8133](https://doi.org/10.2196/publichealth.8133)] [Medline: [29046267](https://pubmed.ncbi.nlm.nih.gov/29046267/)]
2. Huang GC, Soto D, Fujimoto K, Valente TW. The interplay of friendship networks and social networking sites: longitudinal analysis of selection and influence effects on adolescent smoking and alcohol use. *Am J Public Health* 2014 Aug;104(8):e51-e59. [doi: [10.2105/AJPH.2014.302038](https://doi.org/10.2105/AJPH.2014.302038)] [Medline: [24922126](https://pubmed.ncbi.nlm.nih.gov/24922126/)]
3. Huang J, Kornfield R, Szczytko G, Emery SL. A cross-sectional examination of marketing of electronic cigarettes on Twitter. *Tob Control* 2014 Jul;23 Suppl 3:iii26-iii30 [FREE Full text] [doi: [10.1136/tobaccocontrol-2014-051551](https://doi.org/10.1136/tobaccocontrol-2014-051551)] [Medline: [24935894](https://pubmed.ncbi.nlm.nih.gov/24935894/)]
4. Majmundar A, Chou CP, Cruz TB, Unger JB. Relationship between social media engagement and e-cigarette policy support. *Addictive Behaviors Reports* 2018;100155 [FREE Full text] [doi: [10.1016/j.abrep.2018.100155](https://doi.org/10.1016/j.abrep.2018.100155)] [Medline: [31193757](https://pubmed.ncbi.nlm.nih.gov/31193757/)]
5. Soneji S, Pierce JP, Choi K, Portnoy DB, Margolis KA, Stanton CA, et al. Engagement With Online Tobacco Marketing and Associations With Tobacco Product Use Among U.S. Youth. *J Adolesc Health* 2017 Jul;61(1):61-69. [doi: [10.1016/j.jadohealth.2017.01.023](https://doi.org/10.1016/j.jadohealth.2017.01.023)] [Medline: [28363720](https://pubmed.ncbi.nlm.nih.gov/28363720/)]

6. Unger JB, Urman R, Cruz TB, Majmundar A, Barrington-Trimis J, Pentz M, et al. Talking about tobacco on Twitter is associated with tobacco product use. *Prev Med* 2018 Sep;114:54-56 [FREE Full text] [doi: [10.1016/j.ypmed.2018.06.006](https://doi.org/10.1016/j.ypmed.2018.06.006)] [Medline: [29898418](https://pubmed.ncbi.nlm.nih.gov/29898418/)]
7. Allem JP, Ferrara E, Uppu SP, Cruz TB, Unger JB. E-Cigarette Surveillance With Social Media Data: Social Bots, Emerging Topics, and Trends. *JMIR Public Health Surveill* 2017 Dec 20;3(4):e98 [FREE Full text] [doi: [10.2196/publichealth.8641](https://doi.org/10.2196/publichealth.8641)] [Medline: [29263018](https://pubmed.ncbi.nlm.nih.gov/29263018/)]
8. Luca MA, Martin D, Rossano S, Giancarlo R. People Are Strange When You're a Stranger: Impact and Influence of Bots on Social Networks. 2012 Presented at: Sixth International AAAI Conference on Weblogs and Social Media; 2012; Dublin, IR.
9. Tavares G, Faisal A. Scaling-laws of human broadcast communication enable distinction between human, corporate and robot Twitter users. *PLoS One* 2013 Jul;8(7):e65774 [FREE Full text] [doi: [10.1371/journal.pone.0065774](https://doi.org/10.1371/journal.pone.0065774)] [Medline: [23843945](https://pubmed.ncbi.nlm.nih.gov/23843945/)]
10. Wagner C, Mitter S, Körner C, Strohmaier M. When social bots attack: Modeling susceptibility of users in online social networks. In: *CEUR Workshop Proceedings*. 2012 Presented at: CEUR Workshop Proceedings; April 16, 2012; Lyon, France URL: http://ceur-ws.org/Vol-838/paper_11.pdf
11. Allem J, Escobedo P, Chu K, Soto DW, Cruz TB, Unger JB. Campaigns and counter campaigns: reactions on Twitter to e-cigarette education. *Tob Control* 2017 Mar;26(2):226-229. [doi: [10.1136/tobaccocontrol-2015-052757](https://doi.org/10.1136/tobaccocontrol-2015-052757)] [Medline: [26956467](https://pubmed.ncbi.nlm.nih.gov/26956467/)]
12. Harris JK, Moreland-Russell S, Choucair B, Mansour R, Staub M, Simmons K. Tweeting for and against public health policy: response to the Chicago Department of Public Health's electronic cigarette Twitter campaign. *J Med Internet Res* 2014;16(10):e238 [FREE Full text] [doi: [10.2196/jmir.3622](https://doi.org/10.2196/jmir.3622)] [Medline: [25320863](https://pubmed.ncbi.nlm.nih.gov/25320863/)]
13. Hefler M, Freeman B, Chapman S. Tobacco control advocacy in the age of social media: using Facebook, Twitter and Change. *Tob Control* 2012 Oct 09;22(3):210-214. [doi: [10.1136/tobaccocontrol-2012-050721](https://doi.org/10.1136/tobaccocontrol-2012-050721)]
14. Smyser J. "Toxic Butts": Key Performance Indicators from a California Statewide Social Media Campaign for Tobacco Control. *BJMMR* 2014 Jan 10;4(25):4341-4351. [doi: [10.9734/bjmmr/2014/10650](https://doi.org/10.9734/bjmmr/2014/10650)]
15. Czyzewska M, Ginsburg HJ. Explicit and implicit effects of anti-marijuana and anti-tobacco TV advertisements. *Addict Behav* 2007 Jan;32(1):114-127. [doi: [10.1016/j.addbeh.2006.03.025](https://doi.org/10.1016/j.addbeh.2006.03.025)] [Medline: [16675148](https://pubmed.ncbi.nlm.nih.gov/16675148/)]
16. Henriksen L, Dauphinee AL, Wang Y, Fortmann SP. Industry sponsored anti-smoking ads and adolescent reactance: test of a boomerang effect. *Tob Control* 2006 Feb;15(1):13-18. [doi: [10.1136/tc.2003.006361](https://doi.org/10.1136/tc.2003.006361)] [Medline: [16436398](https://pubmed.ncbi.nlm.nih.gov/16436398/)]
17. Sutfin EL, Szykman LR, Moore MC. Adolescents' responses to anti-tobacco advertising: exploring the role of adolescents' smoking status and advertisement theme. *J Health Commun* 2008;13(5):480-500. [doi: [10.1080/10810730802198961](https://doi.org/10.1080/10810730802198961)] [Medline: [18661389](https://pubmed.ncbi.nlm.nih.gov/18661389/)]
18. Grandpre J, Alvaro EM, Burgoon M, Miller CH, Hall JR. Adolescent reactance and anti-smoking campaigns: a theoretical approach. *Health Commun* 2003;15(3):349-366. [doi: [10.1207/S15327027HC1503_6](https://doi.org/10.1207/S15327027HC1503_6)] [Medline: [12788679](https://pubmed.ncbi.nlm.nih.gov/12788679/)]
19. Wehbe MS, Basil M, Basil D. Reactance and Coping Responses to Tobacco Counter-Advertisements. *J Health Commun* 2017 Jul;22(7):576-583. [doi: [10.1080/10810730.2017.1329853](https://doi.org/10.1080/10810730.2017.1329853)] [Medline: [28586258](https://pubmed.ncbi.nlm.nih.gov/28586258/)]
20. Brehm SS, Brehm JW. *Psychological reactance: a theory of freedom and control*. New York: Academic Press; 1981.
21. Fogarty JS. Reactance theory and patient noncompliance. *Soc Sci Med* 1997 Oct;45(8):1277-1288. [doi: [10.1016/s0277-9536\(97\)00055-5](https://doi.org/10.1016/s0277-9536(97)00055-5)] [Medline: [9381240](https://pubmed.ncbi.nlm.nih.gov/9381240/)]
22. Park YJ, Jang SM, Lee H, Yang GS. Divide in Ferguson: Social Media, Social Context, and Division. *Social Media + Society* 2018 Jul 25;4(3):205630511878963. [doi: [10.1177/2056305118789630](https://doi.org/10.1177/2056305118789630)]
23. Jawad M, Abass J, Hariri A, Akl EA. Social Media Use for Public Health Campaigning in a Low Resource Setting: The Case of Waterpipe Tobacco Smoking. *Biomed Res Int* 2015;2015:562586 [FREE Full text] [doi: [10.1155/2015/562586](https://doi.org/10.1155/2015/562586)] [Medline: [26273631](https://pubmed.ncbi.nlm.nih.gov/26273631/)]
24. Shi J, Poorisat T, Salmon CT. The Use of Social Networking Sites (SNSs) in Health Communication Campaigns: Review and Recommendations. *Health Commun* 2018 Jan 18;33(1):49-56. [doi: [10.1080/10410236.2016.1242035](https://doi.org/10.1080/10410236.2016.1242035)] [Medline: [27858464](https://pubmed.ncbi.nlm.nih.gov/27858464/)]
25. O'Donnell NH, Willoughby JF. Photo-sharing social media for eHealth: analysing perceived message effectiveness of sexual health information on Instagram. *J Vis Commun Med* 2017 Oct;40(4):149-159. [doi: [10.1080/17453054.2017.1384995](https://doi.org/10.1080/17453054.2017.1384995)] [Medline: [29022412](https://pubmed.ncbi.nlm.nih.gov/29022412/)]
26. Reuter K, MacLennan A, Le N, Unger JB, Kaiser EM, Angyan P. A Software Tool Aimed at Automating the Generation, Distribution, and Assessment of Social Media Messages for Health Promotion and Education Research. *JMIR Public Health Surveill* 2019 May 07;5(2):e11263 [FREE Full text] [doi: [10.2196/11263](https://doi.org/10.2196/11263)] [Medline: [31066708](https://pubmed.ncbi.nlm.nih.gov/31066708/)]
27. Risch J, Krestel R. *Toxic Comment Detection in Online Discussions*. Singapore: Springer; 2020:A-109.
28. Anderson AA, Yeo SK, Brossard D, Scheufele DA, Xenos MA. Toxic Talk: How Online Incivility Can Undermine Perceptions of Media. *Int J Public Opin Res* 2016 Aug 20;156-168. [doi: [10.1093/ijpor/edw022](https://doi.org/10.1093/ijpor/edw022)]
29. Gonçalves J. Aggression in news comments: how context and article topic shape user-generated content. *Journal of Applied Communication Research* 2018 Oct 03;46(5):604-620. [doi: [10.1080/00909882.2018.1529419](https://doi.org/10.1080/00909882.2018.1529419)]

30. Anderson AA, Huntington HE. Social Media, Science, and Attack Discourse: How Twitter Discussions of Climate Change Use Sarcasm and Incivility. *Science Communication* 2017 Oct 13;39(5):598-620. [doi: [10.1177/1075547017735113](https://doi.org/10.1177/1075547017735113)]
31. Burnap P, Williams ML. Cyber Hate Speech on Twitter: An Application of Machine Classification and Statistical Modeling for Policy and Decision Making. *Policy & Internet* 2015 Apr 22;7(2):223-242. [doi: [10.1002/poi.3.85](https://doi.org/10.1002/poi.3.85)]
32. Davidson HE, Warmsley D, Macy M, Weber I. Automated hate speech detection and the problem of offensive language. In: Eleventh International AAAI Conference on Web and Social Media. 2017 Presented at: Eleventh International AAAI Conference on Web and Social Media; 2017; Montreal, Canada p. 512-515. [doi: [10.4140/TCP.n.2014.426](https://doi.org/10.4140/TCP.n.2014.426)]
33. Keeping Instagram a Safe Place for Self-Expression. Systrom K. 2017. URL: <https://instagram.tumblr.com/post/162395020002/170629-comments> [accessed 2019-05-29]
34. Deb A, Majmundar A, Seo S, Matsui A, Tandon R, Yan S, et al. Social Bots for Online Public Health Interventions. 2018 Presented at: IEEE/ACM International Conference on Advances in Social Networks Analysis and Mining (ASONAM); Aug; 2018; Barcelona, Spain p. 28-31. [doi: [10.1109/ASONAM.2018.8508382](https://doi.org/10.1109/ASONAM.2018.8508382)]
35. Facebook Inc.. Community Standards - Hate Speech. Facebook Inc. 2019. URL: https://www.facebook.com/communitystandards/hate_speech [accessed 2019-05-29]
36. Community Guidelines Instagram; 2019. Instagram. URL: [https://help.instagram.com/477434105621119/?helpref=hc_fnav&bc\[0\]=Instagram%20Help&bc\[1\]=Privacy%20and%20Safety%20Center](https://help.instagram.com/477434105621119/?helpref=hc_fnav&bc[0]=Instagram%20Help&bc[1]=Privacy%20and%20Safety%20Center) [accessed 2019-05-29]
37. Ziegele M, Jost P, Bormann M, Heinbach D. Journalistic counter-voices in comment sections: Patterns, determinants, and potential consequences of interactive moderation of uncivil user comments. *SCM* 2018;7(4):525-554. [doi: [10.5771/2192-4007-2018-4-525](https://doi.org/10.5771/2192-4007-2018-4-525)]
38. Witte K. Putting the fear back into fear appeals: The extended parallel process model. *Communication Monographs* 1992 Dec;59(4):329-349. [doi: [10.1080/03637759209376276](https://doi.org/10.1080/03637759209376276)]
39. Worchel S, Brehm JW. Effect of threats to attitudinal freedom as a function of agreement with the communicator. *Journal of Personality and Social Psychology* 1970;14(1):18-22. [doi: [10.1037/h0028620](https://doi.org/10.1037/h0028620)]
40. O'Keefe D. *Persuasion: Theory and Research*. 3rd ed. Thousand Oaks, CA: SAGE; 2016.
41. Richards AS, Banas JA. Inoculating Against Reactance to Persuasive Health Messages. *Health Communication* 2014 Jun 27;30(5):451-460. [doi: [10.1080/10410236.2013.867005](https://doi.org/10.1080/10410236.2013.867005)]

Abbreviations

FDA: Food and Drug Administration

NIH: National Institutes of Health

Edited by T Sanchez; submitted 24.05.20; peer-reviewed by L Laestadius, R Theis; comments to author 29.06.20; revised version received 27.07.20; accepted 09.11.20; published 07.12.20.

Please cite as:

Majmundar A, Le N, Moran MB, Unger JB, Reuter K

Public Response to a Social Media Tobacco Prevention Campaign: Content Analysis

JMIR Public Health Surveill 2020;6(4):e20649

URL: <http://publichealth.jmir.org/2020/4/e20649/>

doi: [10.2196/20649](https://doi.org/10.2196/20649)

PMID: [33284120](https://pubmed.ncbi.nlm.nih.gov/33284120/)

©Anuja Majmundar, NamQuyen Le, Meghan Bridgid Moran, Jennifer B Unger, Katja Reuter. Originally published in *JMIR Public Health and Surveillance* (<http://publichealth.jmir.org>), 07.12.2020. This is an open-access article distributed under the terms of the Creative Commons Attribution License (<https://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in *JMIR Public Health and Surveillance*, is properly cited. The complete bibliographic information, a link to the original publication on <http://publichealth.jmir.org>, as well as this copyright and license information must be included.

Original Paper

Peer Recruitment Strategies for Female Sex Workers Not Engaged in HIV Prevention and Treatment Services in Côte d'Ivoire: Program Data Analysis

Oluwasolape Olawore¹, ScM; Hibist Astatke², PhD; Tiffany Lillie², PhD; Navindra Persaud², MBBS, MPH, PhD; Carrie Lyons¹, MPH; Didier Kamali³, MPH; Rose Wilcher⁴, MPH; Stefan Baral¹, MD

¹Department of Epidemiology, Johns Hopkins School of Public Health, Baltimore, MD, United States

²FHI 360/LINKAGES, Washington, DC, United States

³FHI 360/LINKAGES, Abidjan, Cote D'Ivoire

⁴FHI 360/LINKAGES, Durham, NC, United States

Corresponding Author:

Oluwasolape Olawore, ScM

Department of Epidemiology

Johns Hopkins School of Public Health

615 N Wolfe Street

Baltimore, MD

United States

Phone: 1 4434959178

Email: oolawor1@jhmi.edu

Abstract

Background: In the context of the mostly generalized HIV epidemic in Côte d'Ivoire, key populations bear a higher burden of HIV than that borne by the general reproductive-aged population. Mathematical models have demonstrated the significant potential impact and cost-effectiveness of improving the coverage of HIV prevention and treatment services for key populations in Côte d'Ivoire. However, in 2019, coverage of these services remained limited by multiple intersecting stigmas affecting key populations, necessitating the study of innovative implementation strategies to better meet the needs of those most marginalized. Here, we leverage programmatic data to compare the effectiveness of the enhanced and traditional peer outreach approaches in reaching and providing community HIV testing to female sex workers not readily engaged in HIV prevention and treatment services in Côte d'Ivoire.

Objective: The aim of this study was to describe the characteristics of female sex workers reached by the LINKAGES project in Côte d'Ivoire with enhanced peer outreach and traditional peer outreach and to compare HIV-related outcomes between the women reached by both strategies.

Methods: Deidentified routine programmatic data collected as part of LINKAGES Côte d'Ivoire between October 2017 and April 2018 were used in these analyses. Demographic characteristics and HIV indicators including HIV testing history, HIV case-finding, linkage to HIV treatment, and treatment initiation were assessed using descriptive statistics. Differences in these indicators were compared by outreach strategy using Pearson chi-square tests.

Results: There were 9761 women reached with enhanced peer outreach and routine peer outreach included in these analyses. The overall case-finding rate in the sample was 7.8% (698/8851). Compared with women reached by routine outreach, those reached by enhanced peer outreach were more likely to have previously been tested for HIV (enhanced: 1695/2509, 67.6%; routine: 4302/7252, 60.0%; $\chi^2_1=43.8$; $P=.001$). The enhanced peer outreach approach was associated with a higher HIV case-finding rate (enhanced: 269/2507 10.7%; routine: 429/6344, 6.8%; $\chi^2_1=32.3$; $P=.001$), higher proportion of linkage to treatment (enhanced: 258/269, 95.9%; routine: 306/429, 71.3%; $\chi^2_1=64.4$; $P=.001$), and higher proportion of treatment initiation (enhanced: 212/269, 78.8%; routine: 315/429, 73.3%; $\chi^2_1=2.6$; $P=.11$). Women reached by both approaches were categorized as high risk for HIV-related behaviors such as condomless sex and number of sex acts in the previous week.

Conclusions: These analyses suggest that the novel peer-referral strategy, the enhanced peer outreach approach, was effective in reaching female sex workers in Côte d'Ivoire with demonstrated acquisition risks for HIV and who had not been effectively

engaged by routine outreach approaches. Scaling up novel strategies such as enhanced peer outreach in the context of differentiated service models may be needed to optimize HIV prevention and treatment outcomes for key populations in Côte d'Ivoire.

(*JMIR Public Health Surveill* 2020;6(4):e18000) doi:[10.2196/18000](https://doi.org/10.2196/18000)

KEYWORDS

female sex workers; HIV; Côte d'Ivoire; programmatic data; peer referral

Introduction

Among countries in West and Central Africa, Côte d'Ivoire has one of the more broadly generalized HIV epidemics [1,2]. However, there is still a disproportionate burden of HIV among key populations, including female sex workers [3-6]. Compared to the HIV prevalence of 3.3% among women of reproductive age, the estimated prevalence for female sex workers is 7.5% [7]. Modeling studies [8,9] using data from Côte d'Ivoire have shown that allocating resources to improve HIV services to achieve the 90-90-90 targets set by the Joint United Nations Programme on HIV/AIDS (UNAIDS) among key populations by 2020 could avert 30% of new infections in the country [10]. Financing such HIV services was shown to be associated with an estimated 2% increase in the country's current health care budget compared to an increase of approximately 14% for services which target Côte d'Ivoire's entire population [9]. Addressing the HIV epidemic among key populations has been demonstrated to represent an essential and cost-effective component for the overall HIV response, particularly in the context of declining HIV funding in the country [9].

While HIV prevention and treatment services are available in existing health infrastructure, several factors interact to act as barriers to the uptake of these services. A systematic review [11] assessing the uptake of HIV testing among female sex workers found that, apart from demographic characteristics and risk behaviors, there were factors such as cost and time in accessing health care facilities, HIV testing policy shortcomings in confidentiality, and cost of health care impact uptake. Additionally, policies that specifically criminalize key populations and intersectional stigmas have resulted in limited coverage of these services among key populations [12,13]. Among female sex workers, legal barriers to practicing sex work have perpetuated physical and sexual violence. More than half of the female sex workers enrolled in a recent survey in Côte d'Ivoire reported experiencing physical violence and almost half had reported sexual violence [14]. Notably, violence against female sex workers impacts both the provision and uptake of HIV services, resulting in suboptimal health outcomes [11,14-16]. For female sex workers living with HIV, the intersectional stigmas associated with living with HIV and being a sex worker limit the uptake of and adherence to antiretroviral therapy, ultimately resulting in poor health outcomes among female sex workers and increasing the likelihood of onward transmission of HIV [17].

Given barriers to the uptake and provision of services for key populations in traditional health care settings, there have been widespread efforts to differentiate HIV prevention and treatment services for key populations, including the implementation of decentralized services. Differentiated HIV service delivery

approaches aim to both be client-centered and to reduce the burden on the health system [18-21]. Elements of differentiated care include tailoring service frequency and intensity to the needs of clients, offering services in a range of locations, and task shifting services to different types of providers, including lay and peer providers who may themselves be members of key population communities [19,20]. While differentiated care models have mainly been used for decentralizing care for individuals stable on antiretroviral therapy or for antiretroviral therapy delivery, differentiated care may also be applied to different steps along the HIV care continuum [21-23].

In key population communities, differentiation efforts have included a focus on community-based and peer-driven approaches to meet and serve key population community members in environments that facilitate disclosure of key population-status and uptake of services by reducing stigma associated with accessing health care at facilities [21,24,25]. For example, in West Africa, HIV self-testing kits distributed through community outreach mechanisms have reached key populations who often had no history of HIV testing [26]. In addition, community-led peer education, condom distribution, and STI/HIV screening and treatment have all demonstrated impact in addressing traditionally marginalized communities at high risk of HIV [23,25]. Other studies have consistently shown that community-led programs that incorporate biomedical, behavioral, and structural approaches can support improved prevention and treatment outcomes [25].

Despite the promise that these decentralized community outreach approaches hold for addressing the epidemic among stigmatized populations, they may still not reach those who are most marginalized. Instead, they may repeatedly reach key populations who are already engaged while missing individuals who do not routinely present for prevention services during community-based outreach and, therefore, who may be at greater risk for HIV acquisition and transmission [24]. To address this limitation, researchers and program implementers are increasingly using approaches that leverage networks of key population members to engage with individuals who may not be easily accessible through traditional outreach methods. Methods which rely on social and sexual networks of key populations have been useful in recruiting individuals in research endeavors that aim to understand HIV-related behaviors among key populations. Respondent-driven sampling, a technique that uses a peer-to-peer referral mechanism to directly recruit individuals in a given social or sexual network, is an example of a peer-based recruitment method and is commonly used in research studies to recruit marginalized populations [27,28]. Where these approaches have been used as interventions by HIV programs, they have been shown to increase the uptake of

HIV testing and have been effective in improving HIV and other STI case-finding [29,30].

The enhanced peer outreach approach is a programmatic strategy modeled after respondent-driven sampling developed by the United States Agency for International Development– and President's Emergency Plan For AIDS Relief–supported LINKAGES project to expand HIV services to key populations who have not previously engaged or who do not frequently engage with HIV programs [24,31]. A significant difference between enhanced peer outreach and research-oriented peer-based recruitment methods is that enhanced peer outreach aims to reach those at highest risk of HIV whereas other approaches aim to engage a more diverse sample of the key population community to increase the generalizability of the results. Similar to respondent-driven sampling though, enhanced peer outreach incorporates performance-based incentives and leverages social networks to improve HIV case-finding. Specifically, these approaches are based on the premise of shared social networks between individuals who have and have not been reached by routine HIV outreach. Leveraging these networks may result in increased HIV case-finding and linkage to care [24]. In this study, we describe characteristics of female sex workers reached by the LINKAGES project in Côte d'Ivoire through enhanced and routine peer outreach, and compare the performance of both strategies in improving case-finding and treatment initiation rates among female sex workers in Côte d'Ivoire between October 2017 and April 2018.

Methods

LINKAGES Project

LINKAGES is a global project that has worked in over 30 countries to reduce HIV transmission, increase case identification, improve treatment initiation and adherence, and achieve viral suppression among key populations [32]. The LINKAGES project works by partnering with governments, local community-based organizations, and the private sector to increase reach to key populations most at risk for HIV acquisition and transmission and expand access to comprehensive HIV prevention and treatment services [32].

The LINKAGES project routinely uses a community-led peer outreach approach to engage with key population members and provide a standardized HIV prevention package including testing, provision of condoms and lubricants, screening for other sexually transmitted infections, and counseling [31,32]. Peer outreach workers are themselves key population members and are recruited and trained by the local community-based organization implementing partners to deliver HIV prevention,

testing, and adherence support services to other key population members who frequent hotspots or visit established clinical partners [24,31].

To expand service delivery to key populations who may not be reached through routine peer outreach, LINKAGES developed an enhanced peer outreach approach [24]. With enhanced peer outreach, trained peer outreach workers invite members of key populations to become peer mobilizers [24]. Peer mobilizers, in turn, are given coupons by the peer outreach workers and asked to reach out to their social and sexual networks to encourage high-risk peers to get tested for HIV and seek other related services. Peer mobilizers and outreach workers are incentivized if the peers recruited are eligible for testing, accessed services, and agreed to an HIV test [24]. Although peer mobilizers are not formally trained, they are familiarized with the project, the enhanced peer outreach process, how to select potential participants, and how to distribute coupons [24]. Successfully recruited peers may themselves be encouraged to become peer mobilizers to bolster recruitment; however, it is not required. The coupons distributed have a unique code that links the tested peer to the outreach worker and peer mobilizer who gave out the coupon. The coupon code aids incentivization and helps track which networks were successful in recruiting newly diagnosed individuals. Eligibility for enhanced peer outreach is based on being a self-reported member of the key population, not having previously engaged with an HIV program, or not having been tested for HIV in the previous 3 months. Individuals are also considered to be eligible if they engaged with the program but had not been tested for HIV in the previous 3 months.

In Côte d'Ivoire, LINKAGES implemented the routine peer outreach approach year-round across 26 health districts while the enhanced peer outreach approach was conducted with 6 community-based organizations focused on female sex workers from March 19, 2018 to April 13, 2018 in 11 of the 26 health districts, including a mix of urban, peri-urban, and rural sites. Although community and facility testing are offered in the program in Côte d'Ivoire, testing was more frequently carried out in the community. Peer outreach workers and peer mobilizers received XOF 1500 (XOF: West African CFA Franc; approximately US \$2.50) for every newly enrolled female sex worker who was eligible for HIV testing and, if the female sex worker was newly diagnosed with HIV, the peer outreach worker and the newly diagnosed female sex worker each received XOF 1500 (\$2.50) to cover the cost of transportation to a treatment facility. The implementation details of enhanced peer outreach during the study period are presented in [Table 1](#).

Table 1. Implementation details of the enhanced peer outreach approach in Côte d'Ivoire.

Characteristic	Details
Population	Female sex workers
Implementation dates	March 19, 2018 - April 13, 2018
Sites	
n	11
Health districts	Abidjan (2; Adjame and Attecoube), Anyama, Adzope, Daloa, Divo, Yamoussoukro, Bouake (3; Bouake Sud, Bouake Nord-Est and, Bouake Nord-Ouest) ^a , Bongouanou
Type	Mix of urban, peri-urban, and rural
Selection criteria	
Low case-finding rate	Sites recognized in previous quarters has having low case-finding rates and a large key population size were prioritized as they could be potential sites with a high unmet need for HIV testing services.
Sites with higher case-finding rates	Sites with a higher number of HIV positive cases in the previous quarter were targeted to maximize reach, increase case-finding, and achieve saturation among the key population networks.
Community-based organizations	
n	8
Organizations	Blety, <i>Espace Confiance</i> , <i>Arc-En-Ciel Plus</i> , Alternative-CI, <i>Asapsu Yamoussoukro</i> , RSB, GBH, SAPHarm
Peer outreach workers, n	78
Peer mobilizers, n	312
Why were these peer outreach workers and peer mobilizers chosen?	Based on performance (size of their network and ability to create more at risk key populations)
Incentives	
For every new key population individual tested	XOF ^b 1500
Key population individual enrolled (tested HIV-positive)	XOF 3000 (1500 each to the individual and the peer outreach worker)

^aSouth Bouake, Northeast Bouake, and Northwest Bouake, respectively.

^bXOF: West African CFA franc.

Data Collection

The data used in this study were deidentified routine programmatic data that had been collected as part of the LINKAGES project in Côte d'Ivoire. These data, representing a single time point for each client during the year, were extracted from routinely collected data entered into electronic databases from paper-based forms by implementing partners in 23 of the 26 health districts in Côte d'Ivoire between October 2017 and September 2018 (2018 fiscal year).

The standard forms used by LINKAGES' implementing partners for program monitoring collected demographic information from clients reached, including age, gender, and key population member status. HIV risks of key populations were also characterized based on self-reported answers to questions related to sex work debut, number of sex acts in the past week, and condom use during their last sex encounter (Table 2). Data related to HIV testing, diagnosis, and treatment initiation were captured on the forms, as well as data to determine whether female sex workers had been reached through routine peer outreach or enhanced peer outreach.

Table 2. Risk evaluation categories for female sex workers reached by the LINKAGES program.

Criteria	Low risk	Medium risk	High risk
Age at sex work debut	25 years or older	Between 20 and 24 years	19 years or younger
Number of sex acts in previous week	Fewer than 7 sex acts	Between 7 and 21 sex acts	More than 21 sex acts
Condom use during last sex encounter	Yes	N/A	No

Data Quality

At the end of each week, partners submitted data summaries to the LINKAGES central program office showing the number of key population individuals who were newly recruited, tested

for HIV, newly diagnosed with HIV, and initiated on antiretroviral therapy. All data were validated on a regular basis following the established processes for data quality assurance. Weekly summary reports submitted by partners to the program office were compared with source documents such as registers

and other intake forms in the partner office to ensure consistency. If discrepancies were observed in the data, then reasons for the discrepancies were ascertained and noted, and the data in the summary reports were adjusted to be consistent with those in the source documents.

Statistical Analyses

All program participants included in these analyses were female sex workers who were reached in districts where both approaches were carried out. A female sex worker was defined as a cisgender woman whose majority of income in the past 12 months came from goods or money received in exchange for sex. In these analyses, individuals were tested if they reported no history of HIV tests, or if they had previous testing history but had not been tested for HIV in the previous 3 months, and they did not already know whether they were HIV positive. The HIV case-finding rate was defined as the proportion of previously undiagnosed HIV cases among those who were tested.

Demographic characteristics of all program clients included in our analyses, including age and geographic region, and HIV indicators of number newly tested, number of new diagnoses of HIV, prevalence, linkage to HIV treatment, and HIV treatment initiation were assessed using descriptive statistics. Pearson chi-square tests were used to compare the crude relationship between outreach approach and age, HIV testing history, HIV risk evaluation categories, HIV case-finding rate among those tested, linkage to care, and treatment initiation. A significance level of $P < .05$ was used for all analyses. Analyses were carried out using STATA (version 15; Stata Corp LLC) and Excel (2016, Microsoft Inc).

Ethical Considerations

This analysis was reviewed by the FHI 360 Protection of Human Subjects Committee and classified as nonhuman research since the data did not contain individual identifiers.

Results

Overall Demographic Characteristics and HIV Outcomes

Data records were available for a total of 18,889 female sex workers who were reached by the LINKAGES program between October 2017 and April 2018. Data between May and September 2018 were excluded from these analyses because the time period coincided with a different outreach approach. Additionally, of the 23 health districts where the LINKAGES program was implemented, data for both enhanced peer outreach and routine outreach were available in 8: Adjame, Attecoube, Adzope, Divo, Bouake N-Ouest, Anyama, Daloa, and Yamoussoukro (Table 3). Therefore, the analyses were carried out using data for the 9761 women reached in these 8 health districts where the data from the 2 outreach approaches were available. Of the 9761 women, 83% (8049) were older than 20 years of age; the majority (8851/9761, 91%) of female sex workers in the analytical sample were tested in the 2018 fiscal year. Of the tested participants, 90% (7967/8851) tested negative while 8% (698/8851) were diagnosed with HIV. The prevalence of HIV in the sample, including previously diagnosed female sex workers, was 8.7% (847/9761). Among the female sex workers who were newly diagnosed with HIV, 81% (564/698) were linked to treatment while 76% (527/698) were initiated on treatment, representing 93% (527/564) of all those who were reported to be linked to care.

Table 3. Geographic distribution of a sample of female sex workers reached by enhanced peer outreach approach and routine peer-based outreach strategies in Côte d'Ivoire between October 2017 and April 2018.

Site	Total (N= 9761)	Enhanced peer outreach (n=2509), n (%) ^a	Routine peer outreach (n=7252), n (%) ^a
Adjame	2278	627 (27.5)	1651 (72.5)
Adzope	146	142 (97.3)	4 (2.7)
Anyama	319	24 (7.5)	295 (92.5)
Attecoube	1051	385 (36.6)	666 (63.4)
Bouake N-Ouest	996	458 (46.0)	538 (54.0)
Daloa	1651	299 (18.1)	1352 (81.9)
Divo	1783	392 (22.0)	1391 (78.0)
Yamoussoukro	1537	182 (11.8)	1355 (88.2)

^aPercentage of women of the district total (in column 2).

Comparison of Routine and Enhanced Peer Outreach Approaches

The age distribution and HIV outcomes of the female sex workers reached by enhanced peer outreach and the routine peer outreach in the districts where both approaches were carried out and included in the analysis are presented in Table 4. Standard outreach occurred throughout the duration of the study while enhanced peer outreach took place between March 19,

2018 and April 13, 2018. The total number of women reached in the districts where both approaches were carried out was 9761 and those reached by enhanced peer outreach represented 26% of the sample (2509/9761). Participants reached by enhanced peer outreach were more likely to be older than 20 ($n=9761$; $\chi^2_1=33.4$; $P=.001$), and more likely to report that they had previously been tested for HIV ($n=9761$; $\chi^2_1=43.8$; $P=.001$). Compared to female sex workers reached by standard peer outreach, women reached by enhanced peer outreach were more

likely to be categorized as medium risk for numbers of sex acts in the past week, while those reached by the standard approach were more likely to be categorized as high risk for number of sex acts in the past week ($n=9761$; $\chi^2_2=306.6$; $P=.001$). Women reached by enhanced peer outreach were also more likely to be categorized as medium or high risk for low age of sex work debut ($n=9761$; $\chi^2_2=341.1$; $P=.001$) and high risk for condom use at last sex act ($n=9761$; $\chi^2_1=293.0$; $P=.001$).

The HIV case-finding rate was higher with enhanced peer outreach compared to that of routine peer outreach ($n=8665$; $\chi^2_1=35.25$; $P=.001$). Furthermore, compared to routine peer outreach, enhanced peer outreach was more likely to lead to linkage to treatment ($n=698$; $\chi^2_1=64.4$; $P=.001$) and treatment initiation; however, the difference in treatment initiation was not statistically significant ($n=698$; $\chi^2_1=2.6$; $P=.11$).

Additional sensitivity analyses during 2 different 26-day time periods (at the beginning of the fiscal year and 1 month before

implementation of the enhanced peer outreach approach, excluding the month of March to prevent any potential overlap) were carried out ([Multimedia Appendix 1](#)). In the analysis using the beginning of the fiscal year ([Multimedia Appendix 1](#)), 3187 female sex workers were reached by both approaches with women reached by routine approach representing 21% (684/3187) of the sample. The demographic and behavioral risk distribution were similar to those observed in the main analyses ($n=3078$; $\chi^2_1=3.07$; $P<.001$), and the case-finding rate for routine approach was 8.2% (47/567) while the rate for the enhanced peer outreach approach remained as 10.7% (268/2489). Linkage to treatment was high in both groups but remained higher for women reached by enhanced peer outreach ($n=315$; $\chi^2_1=8.64$; $P<.001$). Treatment initiation was lower for women reached by enhanced peer outreach; however, the difference was not statistically significant ($n=315$; $\chi^2_1=8.64$; $P=.32$). Similar results were observed using the 26-day time period before enhanced peer outreach approach implementation ([Multimedia Appendix 1](#)).

Table 4. Comparison of age and other HIV-related indicators by outreach approach.

Characteristics	Enhanced peer outreach (n=2509)	Routine peer outreach (n=7252)	Chi-square test (<i>df</i>)	<i>P</i> value
Age categories			33.4 (1)	.001
≤20	345 (13.8)	1366 (18.8)		
>20	2164 (86.3)	5885 (81.2)		
Missing ^a	0	1 (<1)		
Ever previously tested			43.8 (1)	.001
No	804 (32.0)	2855 (39.4)		
Yes	1695 (67.6)	4352 (60.0)		
Missing ^a	10 (0.4)	45 (0.6)		
Number of sex acts in the past week			306.6 (2)	.001
Low risk (<7 sex acts)	529 (21.1)	2400 (33.1)		
Medium risk (7-21 sex acts)	1367 (54.5)	2471 (34.1)		
High risk (>21 sex acts)	581 (23.1)	2114 (29.2)		
Missing ^a	32 (1.3)	267 (3.7)		
Age of sex work debut			341.1 (2)	.001
Low risk (≥25 years old)	400 (15.9)	2524 (34.8)		
Medium risk (20-24 years old)	1312 (52.3)	2781 (38.4)		
High risk (≤19 years old)	762 (30.4)	1684 (23.2)		
Missing ^a	35 (1.4)	263 (3.6)		
Condom use at last sex act			293.0 (1)	.001
Low risk (yes)	1106 (44.1)	3883 (53.5)		
High risk (no)	1387 (55.3)	3101 (42.8)		
Missing ^a	16 (0.6)	268 (3.7)		
HIV case-finding rate (n=8851)^b			35.3 (1)	.001
Positive test result	269 (10.7)	429 (6.8)		
Negative test result	2225 (89.2)	5742 (93.1)		
Missing ^a	13 (0.52)	173 (2.7)		
Linked to treatment (n=698)^c			64.4 (1)	.001
No	11 (4.1)	123 (28.7)		
Yes	258 (95.9)	306 (71.3)		
Treatment initiation (n=698)^c			2.6 (1)	.11
No	57 (21.2)	114 (26.6)		
Yes	212 (78.8)	315 (73.4)		

^aMissing categories excluded from statistical tests.

^bAmong female sex workers who were tested.

^cAmong female sex workers who were newly diagnosed with HIV.

Discussion

Principal Findings

In this study, 2 community-based outreach strategies were compared, both focused on engaging female sex workers in

HIV testing and prevention services in Côte d'Ivoire. This study suggests that leveraging peer referral networks for HIV testing through the enhanced peer outreach approach may be an efficient strategy for reaching female sex workers for testing and diagnosis in Côte d'Ivoire. Results suggest that the enhanced peer outreach approach was able to reach female sex workers

who had moderate to high HIV behavioral risks. There were improvements in case-finding rates for both approaches compared to those in the previous fiscal year (6% for enhanced peer outreach and 2% for standard outreach in the previous fiscal year) [24], and compared to the routine outreach, newly diagnosed individuals reached by enhanced peer outreach were more likely to be integrated into HIV care than those who were reached by the routine outreach approach.

The high case-finding rates observed in the program overall and in women reached by enhanced peer outreach compared to routine outreach, coupled with increases in case-finding from the previous year, highlight the potential utility of using targeted and differentiated service delivery approaches. Awareness of HIV status remains a critical step in meeting targets set by UNAIDS to reduce the global burden of HIV by 2030 [10]. Individuals who are diagnosed can be referred for antiretroviral therapy and those who are uninfected can benefit from appropriate risk-reduction counseling and prevention services such as the provision of condoms or pre-exposure prophylaxis treatments. Given that enhanced peer outreach was implemented to reach key populations who do not readily engage with health services, women diagnosed through the approach may have otherwise continued to transmit HIV or may have been identified at a later stage of disease progression, ultimately challenging HIV epidemic control. Mathematical modeling studies in Côte d'Ivoire suggest that HIV prevention and treatment services targeted to key populations could be the most cost-effective way to improve HIV control efforts in the country by averting up to 30% of new infections [9]. Since peer referral approaches have been well established as useful in recruiting marginalized populations for research studies and have previously been leveraged as intervention tools to influence HIV-related behavior and improve HIV outcomes [33,34], enhanced peer outreach could be used not only to increase testing uptake—an important application for differentiated care at the first step of the cascade—but also to promote HIV prevention knowledge, pre-exposure prophylaxis and condoms, thus modifying risk behaviors within networks [28,35]. However, these approaches have rarely been taken to scale limiting their public health impact to date [23,36]. Characterizing optimal implementation strategies to maximize impact and sustainability requires engagement with a broad range of stakeholders under the leadership of government and community actors [23,36].

While linkage to treatment and treatment initiation among female sex workers reached through LINKAGES was encouraging, 25% of the newly diagnosed women did not initiate treatment, indicating gaps in the second 95 target set by UNAIDS [10]. Given the high HIV prevalence observed in this sample, there is need for implementing novel linkage strategies together with the case-finding approaches evaluated here. An allowance of up to 1500 XOF for transportation to antiretroviral therapy facilities was provided to all female sex workers diagnosed with HIV who had been reached by enhanced peer outreach, and to the peer outreach worker involved in HIV diagnosis, to ensure linkage to treatment occurred; no difference was observed with treatment initiation by group, indicating that there might be a need for additional strategies to ensure those who link to treatment facilities initiate antiretroviral therapy

and are retained. While the latest HIV treatment guidelines in Côte d'Ivoire recommend immediate antiretroviral therapy for all persons diagnosed with HIV regardless of CD4 count, it is possible that budgetary constraints in clinical settings in Côte d'Ivoire hamper the implementation of immediate antiretroviral therapy initiation for some of those diagnosed [37].

All of the community-based organizations involved in the outreach approaches evaluated here were key population-led, or at least trained, to be competent in addressing the needs of key population reinforcing the importance of the role of key population-led organizations in improving HIV outcomes within their communities. With high levels of stigma still facing key populations in many regions of the world, key population-led organizations are increasingly recognized as central to reaching and effectively providing care to members of key population communities who may desire to access care but fear discrimination [38]. Moreover, evidence exists that community- and peer-driven approaches such as these are effective in improving not only testing but also in reducing incidence and improving treatment initiation and adherence [25,39].

These data were collected through programmatic surveillance and represent real-world settings. This study is an example of how data collected by community-based HIV programs may be used to answer epidemiological questions. Dedicated epidemiological studies can be prohibitively expensive and leveraging programmatic data collection to understand populations and inform program implementation provides an opportunity for efficiently and effectively addressing the epidemic. Moreover, as funding to carry out research studies becomes limited and the HIV epidemic continues, there is a need to better utilize routinely collected program data to address existing knowledge gaps [40].

Our findings should be interpreted with consideration of several limitations. The data used in this evaluation were program data. While program data may fill existing knowledge gaps, these data were not collected for research purposes. Therefore, lapses in information and inconsistencies in data collection or data entry may have affected our results. Even with routine data quality assurance measures taken by the program, discrepancies in data entry and missing data were common, limiting our ability to use some variables that may have contributed to the rigor of these analyses and impacting the interpretation of our findings. Furthermore, these data were collected in one time period in one fiscal year. It is possible that similar results may not be observed in other time periods. Comparisons of findings at other time points could have strengthened these analyses. However, results from a recent study [24] using data from the previous fiscal year indicate an increasing trend in new HIV diagnoses. Given that the enhanced peer outreach approach was carried during a 1-month period of the fiscal year, an analysis comparing both approaches within the same time period would have been preferable. However, focusing on the part of the program to reach more high-risk individuals during the time period that enhanced peer outreach was carried out meant that virtually all key populations reached during the time period were recruited through the enhanced peer outreach approach limiting our ability to effectively carry out a comparison during the same time period. Nevertheless, we have included sensitivity analyses

using the 26-day period at the beginning of the fiscal year and an additional 26-day period before the implementation of enhanced peer outreach approach as comparisons, and the interpretations of our findings remained the same. Incentives provided to peer outreach workers and peer mobilizers could have introduced participation bias and differential recruitment by approach impacting the representativeness of our findings and enhanced peer outreach approach if implemented as an intervention in Côte d'Ivoire. Thus, implementation could be carried out systematically and targeted in only populations where effectiveness has been shown. Additionally, monetary incentives could be substituted with small nonmonetary prizes which are potentially more scalable. Engagement with local stakeholders is needed to ensure the most cost-effective approach to scaling. The LINKAGES program in Côte d'Ivoire is a community-based program and only followed key population peers until linkage to treatment. Other partners tracked and monitored viral load in persons living with HIV after antiretroviral therapy initiation; therefore, the ability of the LINKAGES to monitor treatment initiation is limited. The lack of statistical significance in treatment initiation comparing enhanced peer outreach approach and standard outreach ($n=698$; $\chi^2_1=2.6$; $P=.11$) may therefore be due to gaps in data. Findings may not be generalizable to other regions, and since the program participants represented in our data were female sex workers, our results may not apply to other key populations. However, peer referral has been shown

to be effective for reaching other key populations including men who have sex with men and people who inject drugs [33,41,42]. The data used here to evaluate the risk profiles of the female sex workers were limited due to high levels of missing data. Furthermore, responses to the individual questions which made up the risk evaluations for women reached by the routine peer approach were only available as categorized variables therefore misclassification of risk could have occurred. Finally, all behavioral data collected were self-reported by clients of the program, making the findings susceptible to recall and social desirability biases.

Conclusion

In the context of a large-scale HIV response, there has only been a 32% decrease in new infections over the last nine years in Côte d'Ivoire. Epidemiologic and cost-effectiveness data suggest that targeted approaches may support increased impact within existing budget envelopes. These analyses demonstrated that the peer referral-based strategy—enhanced peer outreach—was effective in reaching those who are at higher risk for HIV acquisition and transmission and who may not frequently utilize existing HIV services. Achieving greater gains with increasingly limited resources necessitates more widespread implementation of novel approaches that engage communities traditionally disconnected from HIV prevention and treatment services in Côte d'Ivoire.

Acknowledgments

The authors wish to acknowledge all those who participated in the implementation of enhanced peer outreach in Côte d'Ivoire, particularly the technical and strategic information staff. The authors appreciate the commitment of key population members in Côte d'Ivoire, especially the peer outreach workers, peer mobilizers, and staff of the community-based organizations and implementing groups.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Sensitivity analyses using two different time points for comparison.

[DOCX File, 24 KB - [publichealth_v6i4e18000_app1.docx](#)]

References

1. Maheu-Giroux M, Baral S, Vesga JF, Diouf D, Diabaté S, Alary M, et al. Anal intercourse among women working in the sex industry in Côte d'Ivoire: prevalence, determinants, and model-based estimates of the population-level impact on HIV transmission. *Am J Epidemiol* 2018 Feb 01;187(2):287-297 [FREE Full text] [doi: [10.1093/aje/kwx244](https://doi.org/10.1093/aje/kwx244)] [Medline: [28633387](https://pubmed.ncbi.nlm.nih.gov/28633387/)]
2. Maheu-Giroux M, Vesga JF, Diabaté S, Alary M, Baral S, Diouf D, et al. Changing dynamics of HIV transmission in Côte d'Ivoire: modeling who acquired and transmitted infections and estimating the impact of past HIV interventions (1976-2015). *J Acquir Immune Defic Syndr* 2017 Aug 15;75(5):517-527 [FREE Full text] [doi: [10.1097/QAI.0000000000001434](https://doi.org/10.1097/QAI.0000000000001434)] [Medline: [28471837](https://pubmed.ncbi.nlm.nih.gov/28471837/)]
3. Beyrer C, Baral SD, van Griensven F, Goodreau SM, Chariyalertsak S, Wirtz AL, et al. Global epidemiology of HIV infection in men who have sex with men. *Lancet* 2012 Jul 28;380(9839):367-377 [FREE Full text] [doi: [10.1016/S0140-6736\(12\)60821-6](https://doi.org/10.1016/S0140-6736(12)60821-6)] [Medline: [22819660](https://pubmed.ncbi.nlm.nih.gov/22819660/)]
4. Baral S, Sifakis F, Cleghorn F, Beyrer C. Elevated risk for HIV infection among men who have sex with men in low- and middle-income countries 2000-2006: a systematic review. *PLoS Med* 2007 Dec;4(12):e339 [FREE Full text] [doi: [10.1371/journal.pmed.0040339](https://doi.org/10.1371/journal.pmed.0040339)] [Medline: [18052602](https://pubmed.ncbi.nlm.nih.gov/18052602/)]

5. Baral S, Beyrer C, Muessig K, Poteat T, Wirtz A, Decker MR, et al. Burden of HIV among female sex workers in low-income and middle-income countries: a systematic review and meta-analysis. *Lancet Infect Dis* 2012 Jul;12(7):538-549. [doi: [10.1016/S1473-3099\(12\)70066-X](https://doi.org/10.1016/S1473-3099(12)70066-X)] [Medline: [22424777](https://pubmed.ncbi.nlm.nih.gov/22424777/)]
6. The gap report. UNAIDS. URL: http://www.unaids.org/sites/default/files/media_asset/UNAIDS_Gap_report_en.pdf [accessed 2019-12-21]
7. Côte d'Ivoire. UNAIDS. URL: <https://www.unaids.org/en/regionscountries/countries/ctedivoire> [accessed 2020-07-20]
8. Maheu-Giroux M, Vesga J, Diabaté S, Alary M, Baral S, Diouf D, et al. Population-level impact of an accelerated HIV response plan to reach the UNAIDS 90-90-90 target in Côte d'Ivoire: insights from mathematical modeling. *PLoS Med* 2017 Jun;14(6):e1002321 [FREE Full text] [doi: [10.1371/journal.pmed.1002321](https://doi.org/10.1371/journal.pmed.1002321)] [Medline: [28617810](https://pubmed.ncbi.nlm.nih.gov/28617810/)]
9. Maheu-Giroux M, Diabaté S, Boily M, Jean-Paul N, Vesga JF, Baral S, et al. Cost-effectiveness of accelerated HIV response scenarios in Côte d'Ivoire. *J Acquir Immune Defic Syndr* 2019 Apr 15;80(5):503-512. [doi: [10.1097/QAI.0000000000001956](https://doi.org/10.1097/QAI.0000000000001956)] [Medline: [30649034](https://pubmed.ncbi.nlm.nih.gov/30649034/)]
10. 90-90-90: an ambitious treatment target to help end the AIDS epidemic. UNAIDS. URL: https://www.unaids.org/sites/default/files/media_asset/90-90-90_en.pdf [accessed 2019-08-28]
11. Tokar A, Broerse JEW, Blanchard J, Roura M. HIV testing and counseling among female sex workers: a systematic literature review. *AIDS Behav* 2018 Aug;22(8):2435-2457 [FREE Full text] [doi: [10.1007/s10461-018-2043-3](https://doi.org/10.1007/s10461-018-2043-3)] [Medline: [29464430](https://pubmed.ncbi.nlm.nih.gov/29464430/)]
12. Schwartz SR, Nowak RG, Orazulike I, Keshinro B, Ake J, Kennedy S, TRUST Study Group. The immediate effect of the Same-Sex Marriage Prohibition Act on stigma, discrimination, and engagement on HIV prevention and treatment services in men who have sex with men in Nigeria: analysis of prospective data from the TRUST cohort. *Lancet HIV* 2015 Jul;2(7):e299-e306 [FREE Full text] [doi: [10.1016/S2352-3018\(15\)00078-8](https://doi.org/10.1016/S2352-3018(15)00078-8)] [Medline: [26125047](https://pubmed.ncbi.nlm.nih.gov/26125047/)]
13. Crowell TA, Keshinro B, Baral SD, Schwartz SR, Stahlman S, Nowak RG, et al. Stigma, access to healthcare, and HIV risks among men who sell sex to men in Nigeria. *J Int AIDS Soc* 2017 Apr 20;20(1):21489 [FREE Full text] [doi: [10.7448/IAS.20.01.21489](https://doi.org/10.7448/IAS.20.01.21489)] [Medline: [28453241](https://pubmed.ncbi.nlm.nih.gov/28453241/)]
14. Lyons CE, Grosso A, Drame FM, Ketende S, Diouf D, Ba I, et al. Physical and sexual violence affecting female sex workers in Abidjan, Côte d'Ivoire: prevalence, and the relationship with the work environment, HIV, and access to health services. *J Acquir Immune Defic Syndr* 2017 May 01;75(1):9-17 [FREE Full text] [doi: [10.1097/QAI.0000000000001310](https://doi.org/10.1097/QAI.0000000000001310)] [Medline: [28169873](https://pubmed.ncbi.nlm.nih.gov/28169873/)]
15. Lasater ME, Grosso A, Ketende S, Lyons C, Pitche VP, Tchalla J, et al. Characterising the relationship between migration and stigma affecting healthcare engagement among female sex workers in Lomé, Togo. *Glob Public Health* 2019 Oct;14(10):1428-1441. [doi: [10.1080/17441692.2019.1611896](https://doi.org/10.1080/17441692.2019.1611896)] [Medline: [31057037](https://pubmed.ncbi.nlm.nih.gov/31057037/)]
16. Wanyenze RK, Musunguzi G, Kiguli J, Nuwaha F, Mujisha G, Musunguzi J, et al. "When they know that you are a sex worker, you will be the last person to be treated": Perceptions and experiences of female sex workers in accessing HIV services in Uganda. *BMC Int Health Hum Rights* 2017 May 05;17(1):11 [FREE Full text] [doi: [10.1186/s12914-017-0119-1](https://doi.org/10.1186/s12914-017-0119-1)] [Medline: [28476153](https://pubmed.ncbi.nlm.nih.gov/28476153/)]
17. Mtetwa S, Busza J, Chidiya S, Mungofa S, Cowan F. "You are wasting our drugs": health service barriers to HIV treatment for sex workers in Zimbabwe. *BMC Public Health* 2013 Jul 31;13:698 [FREE Full text] [doi: [10.1186/1471-2458-13-698](https://doi.org/10.1186/1471-2458-13-698)] [Medline: [23898942](https://pubmed.ncbi.nlm.nih.gov/23898942/)]
18. Consolidated guidelines on HIV prevention, diagnosis, treatment and care for key populations. World Health Organization. URL: <http://www.who.int/hiv/pub/guidelines/keypopulations-2016/en/> [accessed 2020-07-11]
19. Macdonald V, Verster A, Baggaley R. A call for differentiated approaches to delivering HIV services to key populations. *J Int AIDS Soc* 2017 Jul 21;20(Suppl 4):21658 [FREE Full text] [doi: [10.7448/IAS.20.5.21658](https://doi.org/10.7448/IAS.20.5.21658)] [Medline: [28770592](https://pubmed.ncbi.nlm.nih.gov/28770592/)]
20. Baggaley R, Armstrong A, Dodd Z, Ngoksin E, Krug A. Young key populations and HIV: a special emphasis and consideration in the new WHO Consolidated Guidelines on HIV Prevention, Diagnosis, Treatment and Care for Key Populations. *J Int AIDS Soc* 2015;18(2 Suppl 1):19438 [FREE Full text] [doi: [10.7448/IAS.18.2.19438](https://doi.org/10.7448/IAS.18.2.19438)] [Medline: [25724509](https://pubmed.ncbi.nlm.nih.gov/25724509/)]
21. Grimsrud A, Bygrave H, Doherty M, Ehrenkranz P, Eelman T, Ferris R, et al. Reimagining HIV service delivery: the role of differentiated care from prevention to suppression. *J Int AIDS Soc* 2016;19(1):21484 [FREE Full text] [doi: [10.7448/IAS.19.1.21484](https://doi.org/10.7448/IAS.19.1.21484)] [Medline: [27914186](https://pubmed.ncbi.nlm.nih.gov/27914186/)]
22. Schwartz SR, Baral S. Remembering individual perspectives and needs in differentiated HIV care strategies. *BMJ Qual Saf* 2019 Apr;28(4):257-259. [doi: [10.1136/bmjqs-2018-008339](https://doi.org/10.1136/bmjqs-2018-008339)] [Medline: [30591539](https://pubmed.ncbi.nlm.nih.gov/30591539/)]
23. Ehrenkranz P, Grimsrud A, Rabkin M. Differentiated service delivery: navigating the path to scale. *Curr Opin HIV AIDS* 2019 Jan;14(1):60-65. [doi: [10.1097/COH.0000000000000509](https://doi.org/10.1097/COH.0000000000000509)] [Medline: [30394947](https://pubmed.ncbi.nlm.nih.gov/30394947/)]
24. Lillie T, Persaud N, DiCarlo M, Gashobotse D, Kamali D, Cheron M, et al. Reaching the unreached: performance of an enhanced peer outreach approach to identify new HIV cases among female sex workers and men who have sex with men in HIV programs in West and Central Africa. *PLoS One* 2019;14(4):e0213743 [FREE Full text] [doi: [10.1371/journal.pone.0213743](https://doi.org/10.1371/journal.pone.0213743)] [Medline: [30943205](https://pubmed.ncbi.nlm.nih.gov/30943205/)]
25. Wirtz AL, Pretorius C, Beyrer C, Baral S, Decker MR, Sherman SG, et al. Epidemic impacts of a community empowerment intervention for HIV prevention among female sex workers in generalized and concentrated epidemics. *PLoS One* 2014;9(2):e88047 [FREE Full text] [doi: [10.1371/journal.pone.0088047](https://doi.org/10.1371/journal.pone.0088047)] [Medline: [24516580](https://pubmed.ncbi.nlm.nih.gov/24516580/)]

26. Lyons CE, Coly K, Bowring AL, Liestman B, Diouf D, Wong VJ, et al. Use and acceptability of HIV self-testing among first-time testers at risk for HIV in Senegal. *AIDS Behav* 2019 Sep;23(Suppl 2):130-141 [FREE Full text] [doi: [10.1007/s10461-019-02552-2](https://doi.org/10.1007/s10461-019-02552-2)] [Medline: [31197701](https://pubmed.ncbi.nlm.nih.gov/31197701/)]
27. Heckathorn D. Respondent-driven sampling: a new approach to the study of hidden populations. *Social Problems* 1997 May;44(2):174-199 [FREE Full text] [doi: [10.2307/3096941](https://doi.org/10.2307/3096941)]
28. Stahlman S, Johnston LG, Yah C, Ketende S, Maziya S, Trapence G, et al. Respondent-driven sampling as a recruitment method for men who have sex with men in southern sub-Saharan Africa: a cross-sectional analysis by wave. *Sex Transm Infect* 2016 Jun;92(4):292-298. [doi: [10.1136/sextrans-2015-052184](https://doi.org/10.1136/sextrans-2015-052184)] [Medline: [26424712](https://pubmed.ncbi.nlm.nih.gov/26424712/)]
29. Pines HA, Goodman-Meza D, Pitpitan EV, Torres K, Semple SJ, Patterson TL. HIV testing among men who have sex with men in Tijuana, Mexico: a cross-sectional study. *BMJ Open* 2016 Feb 04;6(2):e010388 [FREE Full text] [doi: [10.1136/bmjopen-2015-010388](https://doi.org/10.1136/bmjopen-2015-010388)] [Medline: [26846899](https://pubmed.ncbi.nlm.nih.gov/26846899/)]
30. Rosenberg NE, Kamanga G, Pettifor AE, Bonongwe N, Mapanje C, Rutstein SE, et al. STI patients are effective recruiters of undiagnosed cases of HIV: results of a social contact recruitment study in Malawi. *J Acquir Immune Defic Syndr* 2014 Apr 15;65(5):e162-e169 [FREE Full text] [doi: [10.1097/QAI.0000000000000066](https://doi.org/10.1097/QAI.0000000000000066)] [Medline: [24759065](https://pubmed.ncbi.nlm.nih.gov/24759065/)]
31. LINKAGES enhanced peer outreach approach (EPOA): implementation guide. FHI 360. URL: <https://www.fhi360.org/sites/default/files/media/documents/resource-linkages-enhanced-peer-outreach.PDF> [accessed 2019-08-28]
32. LINKAGES project. USAID. URL: <https://www.usaid.gov/global-health/health-areas/hiv-and-aids/partnerships-projects/linkages-project> [accessed 2019-08-28]
33. Baral SD, Ketende S, Schwartz S, Orzulike I, Ugoh K, Peel SA, et al. Evaluating respondent-driven sampling as an implementation tool for universal coverage of antiretroviral studies among men who have sex with men living with HIV. *J Acquir Immune Defic Syndr* 2015 Mar 01;68 Suppl 2:S107-S113 [FREE Full text] [doi: [10.1097/QAI.0000000000000438](https://doi.org/10.1097/QAI.0000000000000438)] [Medline: [25723974](https://pubmed.ncbi.nlm.nih.gov/25723974/)]
34. Mavhu W, Willis N, Mufuka J, Bernays S, Tshuma M, Mangenah C, et al. Effect of a differentiated service delivery model on virological failure in adolescents with HIV in Zimbabwe (Zvandiri): a cluster-randomised controlled trial. *Lancet Glob Health* 2020 Feb;8(2):e264-e275 [FREE Full text] [doi: [10.1016/S2214-109X\(19\)30526-1](https://doi.org/10.1016/S2214-109X(19)30526-1)] [Medline: [31924539](https://pubmed.ncbi.nlm.nih.gov/31924539/)]
35. Amir Khanian YA. Social networks, sexual networks and HIV risk in men who have sex with men. *Curr HIV/AIDS Rep* 2014 Mar;11(1):81-92 [FREE Full text] [doi: [10.1007/s11904-013-0194-4](https://doi.org/10.1007/s11904-013-0194-4)] [Medline: [24384832](https://pubmed.ncbi.nlm.nih.gov/24384832/)]
36. Ehrenkranz PD, Calleja JM, El-Sadr W, Fakoya AO, Ford N, Grimsrud A, et al. A pragmatic approach to monitor and evaluate implementation and impact of differentiated ART delivery for global and national stakeholders. *J Int AIDS Soc* 2018 Mar;21(3) [FREE Full text] [doi: [10.1002/jia2.25080](https://doi.org/10.1002/jia2.25080)] [Medline: [29537628](https://pubmed.ncbi.nlm.nih.gov/29537628/)]
37. Ouattara EN, MacLean RL, Danel C, Borre ED, Gabillard D, Huang M, et al. Cost-effectiveness and budget impact of immediate antiretroviral therapy initiation for treatment of HIV infection in Côte d'Ivoire: A model-based analysis. *PLoS One* 2019;14(6):e0219068 [FREE Full text] [doi: [10.1371/journal.pone.0219068](https://doi.org/10.1371/journal.pone.0219068)] [Medline: [31247009](https://pubmed.ncbi.nlm.nih.gov/31247009/)]
38. Beyrer C, Baral S, Kerrigan D, El-Bassel N, Bekker L, Celentano DD. Expanding the space: inclusion of most-at-risk populations in HIV prevention, treatment, and care services. *J Acquir Immune Defic Syndr* 2011 Aug;57 Suppl 2:S96-S99 [FREE Full text] [doi: [10.1097/QAI.0b013e31821db944](https://doi.org/10.1097/QAI.0b013e31821db944)] [Medline: [21857306](https://pubmed.ncbi.nlm.nih.gov/21857306/)]
39. Mulongo S, Kapila G, Hatton T, Canagasabay D, Arney J, Kazadi T, et al. Applying innovative approaches for reaching men who have sex with men and female sex workers in the Democratic Republic of Congo. *J Acquir Immune Defic Syndr* 2015 Mar 01;68 Suppl 2:S248-S251. [doi: [10.1097/QAI.0000000000000449](https://doi.org/10.1097/QAI.0000000000000449)] [Medline: [25723991](https://pubmed.ncbi.nlm.nih.gov/25723991/)]
40. McGillen JB, Sharp A, Honermann B, Millett G, Collins C, Hallett TB. Consequences of a changing US strategy in the global HIV investment landscape. *AIDS* 2017 Nov 28;31(18):F19-F23 [FREE Full text] [doi: [10.1097/QAD.0000000000001669](https://doi.org/10.1097/QAD.0000000000001669)] [Medline: [29112075](https://pubmed.ncbi.nlm.nih.gov/29112075/)]
41. Uusküla A, Johnston L, Raag M, Trummal A, Talu A, Des Jarlais DC. Evaluating recruitment among female sex workers and injecting drug users at risk for HIV using respondent-driven sampling in Estonia. *J Urban Health* 2010 Mar;87(2):304-317 [FREE Full text] [doi: [10.1007/s11524-009-9427-7](https://doi.org/10.1007/s11524-009-9427-7)] [Medline: [20131018](https://pubmed.ncbi.nlm.nih.gov/20131018/)]
42. Kan M, Garfinkel DB, Samoylova O, Gray RP, Little KM. Social network methods for HIV case-finding among people who inject drugs in Tajikistan. *J Int AIDS Soc* 2018 Jul;21 Suppl 5:e25139 [FREE Full text] [doi: [10.1002/jia2.25139](https://doi.org/10.1002/jia2.25139)] [Medline: [30033684](https://pubmed.ncbi.nlm.nih.gov/30033684/)]

Abbreviations

XOF: West African CFA Franc

HIV: Human immunodeficiency virus

STI: sexually transmitted infection

UNAIDS: Joint United Nations Programme on HIV/AIDS

Edited by T Sanchez; submitted 28.01.20; peer-reviewed by C Nweneka, H Jones; comments to author 15.06.20; revised version received 07.08.20; accepted 20.08.20; published 01.10.20.

Please cite as:

Olawore O, Astatke H, Lillie T, Persaud N, Lyons C, Kamali D, Wilcher R, Baral S

Peer Recruitment Strategies for Female Sex Workers Not Engaged in HIV Prevention and Treatment Services in Côte d'Ivoire: Program Data Analysis

JMIR Public Health Surveill 2020;6(4):e18000

URL: <https://publichealth.jmir.org/2020/4/e18000>

doi: [10.2196/18000](https://doi.org/10.2196/18000)

PMID: [33001039](https://pubmed.ncbi.nlm.nih.gov/33001039/)

©Oluwasolape Olawore, Hibist Astatke, Tiffany Lillie, Navindra Persaud, Carrie Lyons, Didier Kamali, Rose Wilcher, Stefan Baral. Originally published in JMIR Public Health and Surveillance (<http://publichealth.jmir.org>), 01.10.2020. This is an open-access article distributed under the terms of the Creative Commons Attribution License (<https://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in JMIR Public Health and Surveillance, is properly cited. The complete bibliographic information, a link to the original publication on <http://publichealth.jmir.org>, as well as this copyright and license information must be included.

Original Paper

Understanding the Extent of Adolescents' Willingness to Engage With Food and Beverage Companies' Instagram Accounts: Experimental Survey Study

Samina Lutfeali^{1*}, MPH; Tisheya Ward^{2*}, BSc; Tenay Greene^{2*}, BA; Josh Arshonsky^{2*}, BA; Azizi Seixas^{2*}, PhD; Madeline Dalton^{3*}, PhD; Marie A Bragg^{2,4*}, PhD

¹Stanford Graduate School of Business, Palo Alto, CA, United States

²Department of Population Health, NYU Grossman School of Medicine, New York, NY, United States

³Dartmouth Geisel School of Medicine, Lebanon, NH, United States

⁴School of Global Public Health, New York University, New York, NY, United States

* all authors contributed equally

Corresponding Author:

Marie A Bragg, PhD

Department of Population Health

NYU Grossman School of Medicine

180 Madison Ave, 3rd Fl

New York, NY, 10016

United States

Phone: 1 646 501 2717

Fax: 1 212 501 2706

Email: Marie.Bragg@nyulangone.org

Abstract

Background: Social media platforms have created a new advertising frontier, yet little is known about the extent to which this interactive form of advertising shapes adolescents' online relationships with unhealthy food brands.

Objective: We aimed to understand the extent to which adolescents' preferences for Instagram food ads are shaped by the presence of comments and varying numbers of "likes." We hypothesized that adolescents would show the highest preferences for ads with more "likes" and comments. We predicted that these differences would be greater among adolescents who were "heavy social media users" (ie, >3 hours daily) vs "light social media users" (ie, <3 hours daily).

Methods: We recruited Black and non-Latinx White adolescents (aged 13-17 years; N=832) from Dynata, a firm that maintains online participant panels. Participants completed an online survey in which they were randomized to view and rate Instagram food ads that either did or did not show comments. Within each condition, adolescents were randomized to view 4 images that had high (>10,000), medium (1000-10,000), or low (<100) numbers of "likes." Adolescents reported ad preferences and willingness to engage with the brand.

Results: Adolescents rated ads with medium or high numbers of "likes" higher than ads with few "likes" ($P=.001$ and $P=.002$, respectively). Heavy social media users (>3 hours/day) were 6.366 times more willing to comment on ads compared to light users ($P<.001$).

Conclusions: Adolescents interact with brands in ways that mimic interactions with friends on social media, which is concerning when brands promote unhealthy products. Adolescents also preferred ads with many "likes," demonstrating the power of social norms in shaping behavior. As proposed in 2019, the Children's Online Privacy and Protection Act should expand online advertising restrictions to include adolescents aged 12 to 16 years.

(*JMIR Public Health Surveill* 2020;6(4):e20336) doi:[10.2196/20336](https://doi.org/10.2196/20336)

KEYWORDS

social media; Instagram; social media marketing; food industry; adolescents; adolescent health

Introduction

Globally, young people are spending almost 3 hours per day on social media on average [1]. In the United States, more than 73% of adolescents report using social media daily, 27% of whom report logging in to at least one platform (eg, Snapchat, Instagram) each hour of their day [2]. Similar proportions of adolescents report using social networking sites daily in the United Kingdom, Australia, India, and Spain [3-6]. Food and beverage companies recognize the power of social media to reach young consumers and have greatly expanded their online presence. For example, one report showed that the digital media spending of McDonald's—which is currently 36.1% of its ad budget—is expected to grow to 43.8% by 2023 [7]. Food companies also disproportionately market their products to youth of color, who already experience disproportionate rates of overweight and obesity [8]. Such targeting is concerning given the findings from numerous lab studies that youth who are exposed to food ads consume more food than youth who are exposed to nonfood ads [9]. In response to evidence on the link between exposure to food marketing and poor diet [10], 16 countries have now enacted policies that limit child-targeted food advertising, but only 5 of those countries include protections for adolescents aged 13 to 17 years, and only 3 address digital media specifically [11]. In the United States, two bipartisan senators proposed updating the Children's Online Privacy and Protection Act (COPPA)—the US federal law designed to limit the marketing and collection of online data from children under the age of 13—in 2019 [12] and 2020 [13]. The proposed updates would eliminate racially targeted marketing practices, further limit companies' ability to collect data from children, and expand COPPA protections to include adolescents younger than 16 years [12,13]. Yet, no studies have experimentally examined which social media features cause adolescents to interact with food companies on social media. Knowing which features trigger adolescents' engagement with ads is critical for designing policies to reduce their exposure to ads.

Social norms theory informs why adolescents may be particularly susceptible to food ads on social media [14,15]. Adolescents are highly sensitive to peer behaviors [16-18], reward sensations [19], popularity cues [20], and pressure to conform [18,21]. Neurologically, the nucleus accumbens—the reward hub of the brain—of adolescents is more sensitive to reward compared to that of adults and children [19]. Common features of social media (eg, “like” button) and its highly interactive design may capitalize on these features of adolescent development. One neuroimaging study showed heightened activity in the nucleus accumbens among adolescents who viewed their own posts with high numbers of “likes” vs low numbers of “likes” [22]. In addition, esthetic differences between posts generated by friends compared to those generated by companies are subtle, making these ads a stealth threat.

Few studies have examined how adolescents engage with social media food ads, leaving major gaps in our understanding of how adolescents relate to brands on social media. One study

found that about 6.2 million adolescents followed 27 food and beverage accounts on Twitter and Instagram [23], and qualitative analyses of 2000 social media food ads revealed that food ads featuring adolescents were 2.38 times more likely to contain interactive features (eg, encouraging viewers to “like” ads) compared to posts that featured adults [24]. Other cross-sectional studies have found that 70% of adolescents in a national sample “liked,” shared, or followed food and beverage brands on social media [25], or voluntarily uploaded images that contained a brand name or referenced a marketing campaign (eg, “Share a Coke”) [26]. Knowing which ad features cause adolescents to engage with food and beverage brands is critical for designing policies that shield adolescents from unhealthy ads.

The aim of the present study was to address these gaps by: (1) examining the extent to which adolescents' willingness to “like” and engage with ads depends on whether the ad features low (<100), medium (1000-10,000), or high (>10,000) numbers of “likes”; (2) determining how the presence of positive comments vs no comments influences adolescents' preferences and willingness to engage with the ad; and (3) comparing whether willingness to “like” or engage with the ads differs among adolescents who report heavy (>3 hours daily) vs light (<3 hours daily) social media use. We hypothesized that adolescents would show the highest preferences for ads with many vs few “likes” and comments, especially among heavy social media users.

Methods

Study Population

We recruited 1044 adolescents aged 13-17 years who identified as either Black/African American or non-Latinx White to complete an online survey. We recruited adolescents through Dynata, a firm that maintains online participant panels and recruits individuals from other websites, banner ads, and social media networks. Dynata uses a three-stage randomization process to recruit for surveys. To reduce selection bias, they invite interested panelists to “take a survey,” and no additional details are provided to the participants. Participants complete a proprietary quality control survey and are randomly assigned to surveys for which they likely qualify. The firm offers incentives (eg, cash, lottery, donations to charity) in exchange for participating in surveys. In the case of this study, parents were sent a link for this study and a consent form if their adolescent likely met eligibility criteria. Parents then provided consent before receiving a link to the assent form and then the survey was sent to the adolescents.

Of the 1044 adolescents who started the survey, 976 completed it and 884 correctly answered our data integrity question (ie, “Type Facebook in the box below.”) Fifty-two adolescents identified as belonging to a race/ethnicity other than Black/African American or non-Latinx White, and were excluded from the analyses. Our final sample included 832 adolescents. Table 1 presents the adolescents' self-reported demographic characteristics and social media usage. Secondary analyses of comparisons by race/ethnicity are in preparation as a separate study.

Table 1. Demographic characteristics and social media usage of participants that completed the survey from January to June 2018.

Demographics	Total sample (N=832)	Comment Condition ^a (n=414)	No Comment Condition ^b (n=418)
Age (years), mean (SD)	14.73 (1.67)	14.73 (1.68)	14.72 (1.66)
Sex, n (%)			
Male	426 (51.2)	209 (50.5)	217 (51.9)
Female	406 (48.8)	205 (49.5)	201 (48.1)
Race, n (%)			
Non-Latinx White	445 (53.5)	220 (53.1)	225 (53.8)
Black/African American	387 (46.6)	194 (46.9)	193 (46.2)
When do you use social media? n (%)			
Right when you wake up	305 (36.7)	158 (38.2)	147 (35.2)
Before school	407 (48.9)	198 (47.8)	209 (50.0)
On the way to school	309 (37.2)	138 (33.3)	171 (40.9)
At school	258 (31.0)	133 (32.1)	125 (29.9)
During lunch	381 (45.8)	179 (43.2)	202 (48.3)
On the way home from school	323 (38.8)	147 (35.5)	176 (42.1)
After school	381 (67.8)	290 (70.1)	274 (65.6)
While doing homework	264 (31.7)	128 (30.9)	136 (32.5)
After doing homework	390 (46.9)	205 (49.5)	185 (44.3)
During dinner	158 (19.0)	87 (21.0)	71 (17.0)
Before bed	497 (59.7)	243 (58.7)	254 (60.8)
Right before going to sleep	234 (28.1)	114 (27.5)	120 (28.7)
Do you have...? [check all that apply] n (%)			
Instagram	582 (70.0)	289 (69.1)	293 (70.8)
Facebook	710 (85.3)	355 (85.8)	355 (84.9)
Snapchat	410 (49.3)	201 (48.1)	209 (50.5)
Tumblr	71 (8.5)	41 (9.9)	30 (7.2)
Twitter	394 (47.4)	205 (49.5)	189 (45.2)
Average number of social accounts per participant based on responses to question above, mean (SD)	2.60 (1.20)	2.66 (1.17)	2.55 (1.19)
Have you ever made a purchase through social media? n (%)	167 (20.1)	87 (21.3)	80 (19.5)

^aComment Condition included ads that were Photoshopped with comments from Instagram users. We included comments that were positive in nature (eg, "I love [brand name]! Please sponsor me! [heart emoji]").

^bNo Comment Condition included ads with the comment panel left blank, to appear as though Instagram users had not commented on the ad.

Survey Procedures

Before data collection, we first tested the survey by having the research team take the survey and give feedback on its usability. Subsequently, Dynata representatives responsible for fielding our survey to their panelists tested the survey compatibility with their internal systems to ensure that participants could not take the survey more than once. They also tracked participants internally based on assigned user IDs to ensure that the participants would receive incentives. Parents provided informed consent, and adolescents provided assent after being given investigator contact details, being told that no identifying information would be collected and the survey would take about

15 minutes to complete, and that the study would involve viewing and rating images of consumer products. Adolescents then completed the online survey with a median completion time of 19 minutes. The online survey was hosted on Qualtrics, and Dynata required adolescents to complete the survey on a computer because the small screens on phones or tablets make it difficult to view the ads. Data were collected and analyzed in 2018. The New York University School of Medicine Institutional Review Board approved the study.

Grouping

To select potential brands to include as stimuli, we searched the Instagram accounts of the fast food, beverage, and snack

accounts with the most followers [24]. We selected McDonald's, Pepsi, Coca-Cola, and Oreo because they have some of the highest numbers of adolescent followers among food and beverage brands [23], and because fast food, sugary beverages, and snacks are the categories of foods that are most heavily targeted to adolescents [27-30]. We used a random number generator to identify 4 numbers between 1 and 50, and used that number to randomly select an Instagram post from the official account for McDonald's, Pepsi, Coca-Cola, and Oreo. For example, if the number was 8, the researchers selected the eighth most recent post on McDonald's official Instagram account.

To create the "comment condition," we used Photoshop to add comments from Instagram users onto the 4 ads we selected in the previous step. We included comments that were positive in nature (eg, "I love [brand name]! Please sponsor me! [heart emoji]") to assess whether the presence of comments would encourage adolescents to "like" and comment on the ad. To create the "no comment condition," we created the same comment panel but left it blank to appear as though Instagram users had not commented on the ad. [Multimedia Appendix 1](#) shows an example of adding comments to an Instagram ad.

Within the "comment condition" and the "no comment condition," we added high (>10,000), medium (1000-10,000), or low (<100) numbers of "likes" from social media users to each image. We based these cutoffs on data from a previous study showing that food and beverage company posts generate these ranges of numbers of "likes" [24]. This created a total of 6 groups to which participants were randomized: (1) comments + high "likes"; (2) comments + medium "likes"; (3) comments + low "likes"; (4) no comments + high "likes"; (5) no comments + medium "likes"; and (6) no comments + low "likes." Qualtrics survey software provides capabilities to randomize participants automatically. We chose to use the automated randomization process to assign participants to the "comment" or "no comment" condition in a parallel randomization design. We were blinded to this process as it was automatic through Qualtrics. Although participants were not informed of the condition to which they were assigned, they could see the number of "likes" and whether posts had comments.

Rating of Ads With Varying Numbers of "Likes" and Comments

Participants viewed an ad in their assigned group, and then answered the following questions: "How much do you like this ad?" (scale: 0-100 where 0 is not at all and 100 is very much); "Would you 'like' this ad on social media?" (yes/no); and "Would you comment on this ad on social media?" (yes/no). We used a continuous scale of 0-100 because previous studies have shown that a continuous rating scale is less subject to confounding variables compared to Likert scales, can capture more nuanced responses; in particular, one limitation of Likert scales is that the participants' perceived difference between a "1—hate the product" and "2—somewhat dislike the product" is larger than the participants' perceived difference between "2—somewhat dislike the product" and "3—neutral" [31,32]. We presented each ad in each condition in a random order to

avoid bias, presenting only one ad and its corresponding questions on a page at a time.

Self-Reported Social Media Use

Finally, participants completed a demographic survey and answered questions about their social media usage ([Table 1](#)). Participants saw 7 pages during the study, including the instructions page, the 4 ad pages, and the demographics and debriefing pages.

The primary outcomes were adolescents' ratings of how much they liked the ad, the percentage of ads they were likely to "like," and the percentage of ads on which they were likely to comment.

Statistical Analysis

Analyses were conducted in SAS 9.4 software. We used multilevel regression for each outcome. Responses that were scored on a scale of 0-100 were analyzed using linear regression, whereas binary outcomes (yes/no) were analyzed using logistic regression. Because each adolescent rated multiple ads, each model included a random effect for the participant to account for the repeated measures.

Analyses that adjusted for time spent on social media used a median split at 3 hours, such that adolescents who reported spending more than 3 hours per day on social media were labeled "heavy social media users" and those who reported spending less than 3 hours per day on social media were labeled "light social media users." Analyses were stratified according to whether or not adolescents were shown ads with comments and "likes" (comments condition) or just "likes" (no comments condition). Chi-square tests and *t* tests were conducted to determine if the randomization was successful and to verify that demographic characteristics did not differ between conditions. Because all of these tests were insignificant, demographic characteristics were not included in the models. The Holm-Bonferroni procedure was used to correct for multiple comparisons. We also compared responses to racially targeted food advertising among Black and White participants in a separate study that is currently under review elsewhere.

Results

Rating of Ads With Varying Numbers of "Likes" and Comments

The survey randomized 915 participants into two arms: 455 participants were allocated to the "comment condition" and 460 participants were allocated to the "no comment condition." All participants who were assigned a condition completed that part of the survey. Since some participants incorrectly answered our data integrity question, we ultimately analyzed data from 414 participants in the "comment condition" and 418 participants in the "no comment condition."

Across all ads in both conditions, adolescents reported liking the ads (mean 65.62, SD 27.06 on a 100-point scale) and 576 of 832 participants (69.2%) reported they would "like" one or more of the ads on social media. When rating ads in the "no comment condition," ads with a higher number of "likes" received significantly higher ratings than ads with fewer "likes,"

and were also associated with higher willingness by the adolescents to “like” the ads themselves (Table 2). In contrast, when rating ads in the “comment condition,” there were no

significant differences in ratings or willingness to “like” the ads based on the number of “likes” the ads received.

Table 2. Ratings of ads with varying “likes” and comments.

Outcome Measures	Ads with <100 “Likes”		Ads with 1000-10,000 “Likes”		Ads with >10,000 “Likes”	
	No comment condition	Comment condition	No comment condition	Comment condition	No comment condition	Comment condition
How much do you like this ad? (0, not at all to 100, very much)	61.88 (1.34)	65.15 (1.25)	66.28 (1.34) ^a	65.77 (1.25)	67.74 (1.33) ^a	66.88 (1.24)
Would you “like” this ad on social media? (% who said “yes”)	65.7%	67.8%	67.3%	69.1%	70.7% ^b	74.6%
Would you comment on this ad on social media? (% who said “yes”)	37.9%	37.8%	34.2%	40.2%	37.1%	40.6%

^aHolm-Bonferroni adjusted $P < .001$ comparing medium or high likes and low likes conditions.

^bHolm-Bonferroni adjusted $P < .02$ comparing high likes and low likes conditions.

Across both conditions, 315 of 832 participants (37.9%) reported a willingness to comment on ads, and there were no significant differences in adolescents’ willingness to comment based on whether or not the ad had comments from other social media users or whether the ad had a high, medium, or low number of “likes.”

In the “no comments condition,” heavy social media users reported liking ads 8.614 points more than light users, controlling for the number of “likes” on the ad and the race of the participant (SE 2.263, $P < .001$). In the “comments condition,” heavy users reported liking ads 13.615 points more than light users, controlling for the number of “likes” on the ad and the race of the participant (SE 2.018, $P < .001$).

Further, when adjusting for the level of “likes” on the ad in the “comments condition,” heavy users were 6.366 times more willing to comment compared to light users ($P < .001$). When adjusting for the level of “likes” on the ad in the “no comments condition,” heavy users were 2.564 times more willing to comment compared to light users ($P < .001$).

There was no evidence of a differential response to the level of “likes” on an ad for any of the three outcome measures when comparing heavy and light users (ie, heavy users were not more responsive to the number of “likes” on an ad than light users).

Self-Reported Social Media Use

Every adolescent in the sample reported having one or more social media account (Table 1). They reported spending on average of 4.81 hours (SD 4.66) per day on social media, although the median was 3.00 hours per day. Among the 832 participants, 167 (20.1%) reported having ever made a purchase through social media. On average, the adolescents had created their first social media account at 12.88 years old (SD 2.37).

Discussion

Principal Findings

This study demonstrated that adolescents preferred food ads on Instagram that featured many vs few “likes.” Adolescents were also more willing to engage with Instagram food ads (ie, through

“likes”) when the ads featured many “likes” compared to few “likes.” Further, “heavy users” of social media preferred and were more willing to “like” ads compared to “light users,” who spend less than 3 hours per day on social media. This was also the first study to examine the interaction between the presence of comments and varying number of “likes.” Results showed that the presence of positive comments did not affect adolescents’ ad preferences, which suggests that “likes” may function as a more powerful social tool than comments. These data provide new insights into the effects of “likes” and comments on adolescents’ preferences for ads and willingness to engage with ads. These findings add to the literature on social media usage among adolescents by demonstrating that adolescents are highly willing to interact with ads. We also identified thresholds for the number of “likes” that may be required to shift adolescents’ willingness to “like” an ad. Specifically, adolescents were more likely to prefer and “like” ads with high (>10,000) vs low (<100) numbers of “likes.” However, there were no differences in their willingness to engage with ads featuring high “likes” (>10,000) vs medium “likes” (1000-10,000). These thresholds are concerning because companies, celebrities, and influencers who promote unhealthy products often have more followers than public health campaigns, and therefore may be able to generate more engagement with adolescents.

One particularly concerning set of findings is that heavy social media users reported higher preference for and willingness to engage with food and beverage ads compared to light social media users. Heavy social media users’ positive ad ratings may, however, simply result from familiarity with these types of ads. Although it is unclear how many social media ads adolescents see annually, one study found that 72% (n=101) of adolescents and children were exposed to one or more food ads during a 5-minute data collection period [33], and 44% of those ads promoted sugary beverages. Future research should capture more exposure data and identify the behavioral responses to advertisements between heavy and light users of social media. Although heavy social media use concerns parents and researchers alike [13,34], there are important positives to social

media use [35], especially for marginalized groups seeking connectedness and acceptance [36-41].

Our findings reinforce other research on social media behaviors and the power of “likes.” The average age at which adolescents in our sample reported creating one or more social media account was 12.88 years, even though most social media sites aim to require users be 13 years of age. Similarly, one survey of 1786 parents of youth aged 8 to 18 years found that nearly half of the children started using social media at 12 years old [42]. In our ad rating questions, the adolescents reported higher preferences for and willingness to “like” ads that featured high numbers of “likes” compared to low numbers of “likes,” which is consistent with similar findings from other studies [43,44] and supports the possibility that social norms may drive “likes” among adolescents.

Additionally, our findings support the need for stronger protections in the COPPA in the United States, and international policies would also benefit from strengthening regulations regarding digital advertising. The findings suggest that adolescents may be highly susceptible to social media food ads, which is concerning given the link between exposure to food ads and poor diet [9]. Because it is possible for adolescents to follow social media accounts from other countries, the countries with enacted policies for food marketing should also address digital media. Further, food companies should expand the Children’s Food and Beverage Advertising Initiatives in the United States by enacting an international policy that would limit the promotion of unhealthy food and beverages posts that could be viewed by social media users in other countries.

Finally, 20.1% of the adolescents in our sample reported having purchased a product via social media. To our knowledge, these are the first data to document that adolescents report making purchases on social media. Although one design firm’s survey of 2000 Instagram users found 18% of users have made a purchase directly through Instagram, the sample did not include adolescents aged 17 years and younger [45]. Adolescents’ exposure to seemingly popular food ads (ie, those with many “likes”) may increase their willingness to purchase products on social media, which could be problematic if they purchase branded items (eg, clothing) that then increase brand loyalty and willingness to purchase, and subsequently consume, more unhealthy food and beverage products. These links between ad exposure and future purchases of unhealthy products are supported by studies that show how adolescents’ peers shape their online purchases [46], and that authentic and individualized social media advertising can enhance consumers’ relationships with brands and increase brand loyalty [47,48]. One industry report suggests that today’s adolescents display higher brand loyalty than previous generations, and that 66% of adolescents stated that once they find a brand they like, they will continue to buy that brand for a long time [49].

Limitations

This study has several limitations. Our small sample (N=832) limits our ability to generalize findings on adolescents’

self-reported social media usage habits to other adolescents. It is also possible that the participants may have responded with social desirability bias to provide answers they thought the researchers might prefer. Survey responses, however, were anonymous, which reduces the possibility of social desirability bias. Although we found significant differences between heavy users and light users across all ad rating outcomes, additional research is needed to determine if these differences translate to increased susceptibility to advertising. Because we recruited participants from an online panel, our participants may use technology more or be more tech-savvy than the general population, which could impact our results. However, how often participants used social media varied in our sample. Finally, Instagram recently announced they will start hiding “likes” on Instagram users’ posts so that users can “focus on the photos and videos...not how many likes they get” [50]. Users will still be able to see the number of “likes” on their own posts, and it is possible that hiding “likes” will reduce adolescents’ engagement with ads because the ads will lack cues that indicate their popularity. Further, other social media sites such as Facebook and TikTok have not mentioned plans to remove “likes,” suggesting that the findings are still relevant to social media sites.

Conclusions

This study demonstrates that adolescents preferred and were more willing to “like” Instagram food ads featuring many “likes” versus few “likes,” and “heavy social media users” preferred and were more willing to engage with food ads compared to “light social media users.” The findings on ad ratings demonstrate the power of “likes” in shaping adolescents’ behavior and preferences, especially considering that the near-constant use of social media is rising in this age group [2]. These results also support the possibility that Instagram’s recent decision to hide the “likes” feature may reduce adolescents’ willingness to “like” ads and therefore to reduce engagement with posts that may promote unhealthy habits. Nevertheless, policymakers should enact stronger protections in the COPPA to reduce adolescents’ exposure to unhealthy food and beverage ads that can shape poor diet habits and increase risks for developing diet-related diseases later in life [51]. Although interventions have been tested to improve media literacy and educate children and adolescents about deceptive marketing tactics, these interventions may not be effective in limiting marketing influence. Such interventions focusing on teaching critical viewing skills and skepticism of food advertising have resulted in only minor increases in self-reported skepticism of ads in children 8 years and older [52,53]. Further, research has shown that even when older children and teenagers are able to accurately recognize advertising, they are often unable to resist its influence when embedded in personalized content and trusted social media networks [54], underscoring the critical importance of policy solutions.

Acknowledgments

We would like to thank the following New York University SeedProgram Research Assistants and staff who have no conflicts of interest to report: Andrea Sharkey, Nasira Spells, Dana McIntyre, Robert Suss, Sana Husain, Rachael Biscocho, Ana Carmargo, Erica Finfer, Ingrid Wells, Chelsea Mangold, Shirley Valerio, Michelle Rosa, Amaal Alruwaily, and Krystle Tsai. This study was supported by a National Institutes of Health (NIH) Early Independence Award (DP5OD021373-05; principal investigator MB) from the NIH Office of the Director. This funding source had no role in the study design; in the collection, analysis, or interpretation of data; in the writing of the report; nor in the decision to submit the article for publication.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Example of adding comments to an Instagram ad.

[[DOCX File, 234 KB - publichealth_v6i4e20336_app1.docx](#)]

References

1. Mander J, Kavanagh D, Chase B. Globalwebindex Flagship Report on the Latest Trends in Social Media. New York City: globalwebindex; 2020. URL: <https://www.globalwebindex.com/reports/social> [accessed 2020-02-24]
2. Anderson M, Jiang J. Teens Social Media Habits and Experiences. Pew Research Center. Washington, DC; 2018 Nov 28. URL: <https://www.pewinternet.org/2018/11/28/teens-social-media-habits-and-experiences/> [accessed 2020-03-24]
3. Boak A, Hamilton H, Adlaf E, Henderson J, Mann R. The mental health and well-being of Ontario students, 1991-2017: Detailed findings from the Ontario Student Drug Use and Health Survey (OSDUHS) (CAMH Research Document Series No. 47). Toronto: Centre for Addiction and Mental Health; 2018. URL: <https://www.camh.ca/-/media/files/pdf---osduhs/mental-health-and-well-being-of-ontario-students-1991-2017---detailed-osduhs-findings-pdf.pdf> [accessed 2020-03-21]
4. Booker CL, Kelly YJ, Sacker A. Gender differences in the associations between age trends of social media interaction and well-being among 10-15 year olds in the UK. BMC Public Health 2018 Mar 20;18(1):321 [FREE Full text] [doi: [10.1186/s12889-018-5220-4](https://doi.org/10.1186/s12889-018-5220-4)] [Medline: [29554883](https://pubmed.ncbi.nlm.nih.gov/29554883/)]
5. Rai DG. Impact of Social Networking Sites (SNS): Are Youth affected by its usage? Issues Ideas Educ 2017 Mar 06;5(1):11-24. [doi: [10.15415/ije.2017.51001](https://doi.org/10.15415/ije.2017.51001)]
6. García-Jiménez A, López-de-Ayala-López M, Catalina-García B. The influence of social networks on the adolescents' online practices. Comunicar: Revista Científica de Comunicación y Educación 2013 Jun 01;21(41):195-204. [doi: [10.3916/c41-2013-19](https://doi.org/10.3916/c41-2013-19)]
7. Klein D. Quick-Service Local Ad Spending to Hit \$4 Billion. Toronto: QSR; 2019 Jun 1. URL: <https://www.qsrmagazine.com/marketing-promotions/quick-service-local-ad-spending-hit-4-billion> [accessed 2020-03-21]
8. Harris J, Frazier WI, Kumanyika S, Ramirez A. Increasing disparities in unhealthy food advertising targeted to Hispanic and Black youth. Rudd Report. Hartford: UConn Rudd Center for Food Policy and Obesity; 2019 Jan 01. URL: <http://uconnruddcenter.org/files/Pdfs/TargetedMarketingReport2019.pdf> [accessed 2020-03-21]
9. Cairns G, Angus K, Hastings G, Caraher M. Systematic reviews of the evidence on the nature, extent and effects of food marketing to children. A retrospective summary. Appetite 2013 Mar;62:209-215 [FREE Full text] [doi: [10.1016/j.appet.2012.04.017](https://doi.org/10.1016/j.appet.2012.04.017)] [Medline: [22561190](https://pubmed.ncbi.nlm.nih.gov/22561190/)]
10. Taillie LS, Busey E, Mediano Stoltze F, Dillman Carpentier FR. Governmental policies to reduce unhealthy food marketing to children. Nutr Rev 2019 Jul 22:nuz021. [doi: [10.1093/nutrit/nuz021](https://doi.org/10.1093/nutrit/nuz021)] [Medline: [31329232](https://pubmed.ncbi.nlm.nih.gov/31329232/)]
11. Smith S, Choueiti M, Pieper K. Inequality in 900 Popular Films: Examining Portrayals of Gender, Race/Ethnicity, LGBT, and Disability from 2007–2016. USC Annenberg School of Communication. 2017. URL: https://annenberg.usc.edu/sites/default/files/Dr_Stacy_L_Smith-Inequality_in_900_Popular_Films.pdf [accessed 2020-03-21]
12. Senator Ed Markey. Senators Markey and Hawley Introduce Bipartisan Legislation to Update Children's Online Privacy Rules. 2019. URL: <https://www.markey.senate.gov/news/press-releases/senators-markey-and-hawley-introduce-bipartisan-legislation-to-update-childrens-online-privacy-rules> [accessed 2020-03-21]
13. Markey E, Blumenthal R. Senators Markey and Blumenthal Introduce First-of-Its-Kind Legislation to Protect Children Online from Harmful Content, Design Features. Ed Markey United States Senator of Massachusetts. 2020. URL: <https://www.markey.senate.gov/news/press-releases/senators-markey-and-blumenthal-introduce-first-of-its-kind-legislation-to-protect-children-online-from-harmful-content-design-features> [accessed 2020-03-22]
14. Schultz PW, Nolan JM, Cialdini RB, Goldstein NJ, Griskevicius V. The constructive, destructive, and reconstructive power of social norms. Psychol Sci 2007 May;18(5):429-434 [FREE Full text] [doi: [10.1111/j.1467-9280.2007.01917.x](https://doi.org/10.1111/j.1467-9280.2007.01917.x)] [Medline: [17576283](https://pubmed.ncbi.nlm.nih.gov/17576283/)]

15. Cialdini R, Kallgren C, Reno R. A Focus Theory of Normative Conduct: A Theoretical Refinement and Reevaluation of the Role of Norms in Human Behavior. In: Zanna MP, editor. *Advances in Experimental Psychology*. Amsterdam: Elsevier Inc; 1991:201-234.
16. Lakon CM, Hipp JR, Wang C, Butts CT, Jose R. Simulating Dynamic Network Models and Adolescent Smoking: The Impact of Varying Peer Influence and Peer Selection. *Am J Public Health* 2015 Dec;105(12):2438-2448 [FREE Full text] [doi: [10.2105/AJPH.2015.302789](https://doi.org/10.2105/AJPH.2015.302789)] [Medline: [26469641](https://pubmed.ncbi.nlm.nih.gov/26469641/)]
17. Brechwald WA, Prinstein MJ. Beyond Homophily: A Decade of Advances in Understanding Peer Influence Processes. *J Res Adolesc* 2011 Mar 01;21(1):166-179 [FREE Full text] [doi: [10.1111/j.1532-7795.2010.00721.x](https://doi.org/10.1111/j.1532-7795.2010.00721.x)] [Medline: [23730122](https://pubmed.ncbi.nlm.nih.gov/23730122/)]
18. Cho H, Li W, Shen L, Cannon J. Mechanisms of Social Media Effects on Attitudes Toward E-Cigarette Use: Motivations, Mediators, and Moderators in a National Survey of Adolescents. *J Med Internet Res* 2019 Jun 27;21(6):e14303 [FREE Full text] [doi: [10.2196/14303](https://doi.org/10.2196/14303)] [Medline: [31250830](https://pubmed.ncbi.nlm.nih.gov/31250830/)]
19. Casey BJ, Jones RM, Hare TA. The adolescent brain. *Ann NY Acad Sci* 2008 Mar;1124:111-126 [FREE Full text] [doi: [10.1196/annals.1440.010](https://doi.org/10.1196/annals.1440.010)] [Medline: [18400927](https://pubmed.ncbi.nlm.nih.gov/18400927/)]
20. Anderson L, McCabe DB. A Coconstructed World: Adolescent Self-Socialization on the Internet. *J Public Policy Market* 2012 Sep;31(2):240-253. [doi: [10.1509/jppm.08.043](https://doi.org/10.1509/jppm.08.043)]
21. Story M, Neumark-Sztainer D, French S. Individual and environmental influences on adolescent eating behaviors. *J Am Diet Assoc* 2002 Mar;102(3 Suppl):S40-S51 [FREE Full text] [doi: [10.1016/s0002-8223\(02\)90421-9](https://doi.org/10.1016/s0002-8223(02)90421-9)] [Medline: [11902388](https://pubmed.ncbi.nlm.nih.gov/11902388/)]
22. Sherman LE, Greenfield PM, Hernandez LM, Dapretto M. Peer Influence Via Instagram: Effects on Brain and Behavior in Adolescence and Young Adulthood. *Child Dev* 2018 Jan;89(1):37-47 [FREE Full text] [doi: [10.1111/cdev.12838](https://doi.org/10.1111/cdev.12838)] [Medline: [28612930](https://pubmed.ncbi.nlm.nih.gov/28612930/)]
23. Rummo PE, Cassidy O, Wells I, Coffino JA, Bragg MA. Examining the Relationship between Youth-Targeted Food Marketing Expenditures and the Demographics of Social Media Followers. *Int J Environ Res Public Health* 2020 Mar 03;17(5):1631 [FREE Full text] [doi: [10.3390/ijerph17051631](https://doi.org/10.3390/ijerph17051631)] [Medline: [32138342](https://pubmed.ncbi.nlm.nih.gov/32138342/)]
24. Bragg MA, Pageot YK, Amico A, Miller AN, Gasbarre A, Rummo PE, et al. Fast food, beverage, and snack brands on social media in the United States: An examination of marketing techniques utilized in 2000 brand posts. *Pediatr Obes* 2020 May;15(5):e12606 [FREE Full text] [doi: [10.1111/ijpo.12606](https://doi.org/10.1111/ijpo.12606)] [Medline: [31875654](https://pubmed.ncbi.nlm.nih.gov/31875654/)]
25. Fleming-Milici F, Harris JL. Adolescents' engagement with unhealthy food and beverage brands on social media. *Appetite* 2020 Mar 01;146:104501 [FREE Full text] [doi: [10.1016/j.appet.2019.104501](https://doi.org/10.1016/j.appet.2019.104501)] [Medline: [31669579](https://pubmed.ncbi.nlm.nih.gov/31669579/)]
26. Holmberg C, E Chaplin J, Hillman T, Berg C. Adolescents' presentation of food in social media: An explorative study. *Appetite* 2016 Apr 01;99:121-129 [FREE Full text] [doi: [10.1016/j.appet.2016.01.009](https://doi.org/10.1016/j.appet.2016.01.009)] [Medline: [26792765](https://pubmed.ncbi.nlm.nih.gov/26792765/)]
27. McGinnis JM, Gootman JA, Kraak VI. *Food Marketing to Youth: Threat or Opportunity?*. Washington, DC: National Academies Press; 2006.
28. Harris J, Schwartz M, LoDolce M, Munsell C, Fleming-Milici F, Elsej J, et al. *Sugary Drink FACTS 2014*. Rudd Center for Food Policy and Obesity. Hartford: University of Connecticut; 2014. URL: http://www.sugarydrinkfacts.org/resources/sugarydrinkfacts_report.pdf [accessed 2020-03-21]
29. Harris J, Schwartz M, Munsell C, Dembek C, Liu S, LoDolce M, et al. *Fast Food FACTS 2013: Measuring Progress in Nutrition and Marketing to Children and Teens*. Yale Rudd Center for Food Policy and Obesity. 2013. URL: http://www.fastfoodmarketing.org/media/fastfoodfacts_report.pdf [accessed 2020-03-21]
30. Harris J, Schwartz M, Shehan C, Hyary M, Appel J, Haraghey K, et al. *Snack FACTS 2015: Evaluating snack food nutrition and marketing to youth*. UConn Rudd Center for Food Policy and Obesity. 2016. URL: http://www.uconnruddcenter.org/files/Pdfs/SnackFACTS_2015_Fulldraft03.pdf
31. Voutilainen A, Pitkääho T, Kvist T, Vehviläinen-Julkunen K. How to ask about patient satisfaction? The visual analogue scale is less vulnerable to confounding factors and ceiling effect than a symmetric Likert scale. *J Adv Nurs* 2016 Apr;72(4):946-957 [FREE Full text] [doi: [10.1111/jan.12875](https://doi.org/10.1111/jan.12875)] [Medline: [26689434](https://pubmed.ncbi.nlm.nih.gov/26689434/)]
32. Kuhlmann T, Dantlgraber M, Reips U. Erratum to: Investigating measurement equivalence of visual analogue scales and Likert-type scales in Internet-based personality questionnaires. *Behav Res Methods* 2017 Dec;49(6):2182 [FREE Full text] [doi: [10.3758/s13428-017-0868-8](https://doi.org/10.3758/s13428-017-0868-8)] [Medline: [28271347](https://pubmed.ncbi.nlm.nih.gov/28271347/)]
33. Potvin Kent M, Pauzé E, Roy E, de Billy N, Czoli C. Children and adolescents' exposure to food and beverage marketing in social media apps. *Pediatr Obes* 2019 Jun;14(6):e12508 [FREE Full text] [doi: [10.1111/ijpo.12508](https://doi.org/10.1111/ijpo.12508)] [Medline: [30690924](https://pubmed.ncbi.nlm.nih.gov/30690924/)]
34. Reid Chassiakos YL, Radesky J, Christakis D, Moreno MA, Cross C, Council of Communications and Media. *Children and Adolescents and Digital Media*. Pediatrics 2016 Nov;138(5):e20162593 [FREE Full text] [doi: [10.1542/peds.2016-2593](https://doi.org/10.1542/peds.2016-2593)] [Medline: [27940795](https://pubmed.ncbi.nlm.nih.gov/27940795/)]
35. Best P, Manktelow R, Taylor B. Online communication, social media and adolescent wellbeing: A systematic narrative review. *Children Youth Serv Rev* 2014 Jun;41:27-36. [doi: [10.1016/j.childyouth.2014.03.001](https://doi.org/10.1016/j.childyouth.2014.03.001)]
36. Craig SL, McInroy L. You Can Form a Part of Yourself Online: The Influence of New Media on Identity Development and Coming Out for LGBTQ Youth. *J Gay Lesbian Ment Health* 2014 Jan 30;18(1):95-109. [doi: [10.1080/19359705.2013.777007](https://doi.org/10.1080/19359705.2013.777007)]
37. Sweet KS, LeBlanc JK, Stough LM, Sweany NW. Community building and knowledge sharing by individuals with disabilities using social media. *J Comput Assist Learn* 2019 Jul 30;36(1):1-11. [doi: [10.1111/jcal.12377](https://doi.org/10.1111/jcal.12377)]

38. Chen YR, Schulz PJ. The Effect of Information Communication Technology Interventions on Reducing Social Isolation in the Elderly: A Systematic Review. *J Med Internet Res* 2016 Jan 28;18(1):e18 [FREE Full text] [doi: [10.2196/jmir.4596](https://doi.org/10.2196/jmir.4596)] [Medline: [26822073](https://pubmed.ncbi.nlm.nih.gov/26822073/)]
39. Bliuc A, Doan T, Best D. Sober social networks: The role of online support groups in recovery from alcohol addiction. *J Community Appl Soc Psychol* 2018 Nov 12;29(2):121-132. [doi: [10.1002/casp.2388](https://doi.org/10.1002/casp.2388)]
40. Williams M. Transition: Development of the Online Natural Hair Community and Black Women's Emerging Identity, Dissertation Politics. ProQuest. Davis, CA: University of California Davis; 2016. URL: <http://search.proquest.com/openview/4a6ef7306058652b188c0a4908b6de27/1?pq-origsite=gscholar&cbl=18750&diss=y> [accessed 2020-03-21]
41. Escobar-Viera CG, Whitfield DL, Wessel CB, Shensa A, Sidani JE, Brown AL, et al. For Better or for Worse? A Systematic Review of the Evidence on Social Media Use and Depression Among Lesbian, Gay, and Bisexual Minorities. *JMIR Ment Health* 2018 Jul 23;5(3):e10496 [FREE Full text] [doi: [10.2196/10496](https://doi.org/10.2196/10496)] [Medline: [30037786](https://pubmed.ncbi.nlm.nih.gov/30037786/)]
42. Rideout V. The Common Sense Census: Media Use by Tweens and Teens, 2015. Common Sense Media. San Francisco: Common Sense Media; 2015. URL: <https://www.commonsensemedia.org/research/the-common-sense-census-media-use-by-tweens-and-teens-2015> [accessed 2020-03-21]
43. Yau JC, Reich SM. "It's Just a Lot of Work": Adolescents' Self-Presentation Norms and Practices on Facebook and Instagram. *J Res Adolesc* 2019 Mar 12;29(1):196-209 [FREE Full text] [doi: [10.1111/jora.12376](https://doi.org/10.1111/jora.12376)] [Medline: [29430759](https://pubmed.ncbi.nlm.nih.gov/29430759/)]
44. Sherman LE, Payton AA, Hernandez LM, Greenfield PM, Dapretto M. The Power of the Like in Adolescence: Effects of Peer Influence on Neural and Behavioral Responses to Social Media. *Psychol Sci* 2016 Jul;27(7):1027-1035 [FREE Full text] [doi: [10.1177/0956797616645673](https://doi.org/10.1177/0956797616645673)] [Medline: [27247125](https://pubmed.ncbi.nlm.nih.gov/27247125/)]
45. Salpini C. Study: Instagram influences almost 75% of user purchase decisions. Retail Dive. 2017. URL: <https://www.retaildive.com/news/study-instagram-influences-almost-75-of-user-purchase-decisions/503336/> [accessed 2020-03-21]
46. Niu H. Cyber peers' influence for adolescent consumer in decision-making styles and online purchasing behavior. *J Appl Soc Psychol* 2013 May 22;43(6):1228-1237. [doi: [10.1111/jasp.12085](https://doi.org/10.1111/jasp.12085)]
47. Laroche M, Habibi MR, Richard M. To be or not to be in social media: How brand loyalty is affected by social media? *Int J Inf Manag* 2013 Feb;33(1):76-82. [doi: [10.1016/j.ijinfomgt.2012.07.003](https://doi.org/10.1016/j.ijinfomgt.2012.07.003)]
48. Wang X, Yu C, Wei Y. Social Media Peer Communication and Impacts on Purchase Intentions: A Consumer Socialization Framework. *J Interact Market* 2012 Nov;26(4):198-208. [doi: [10.1016/j.intmar.2011.11.004](https://doi.org/10.1016/j.intmar.2011.11.004)]
49. Cheung J, Davis T, Heukaeufer E. Gen Z Brand Relationships: Authenticity Matters. National Retail Federation. Armonk: IBM Corporation; 2017. URL: https://nrf.com/sites/default/files/2018-10/NRF_GenZ%20Brand%20Relationships%20Exec%20Report.pdf [accessed 2020-03-21]
50. Meisenzahl M. Here's what your Instagram posts will look like without 'likes'. Business Insider. 2019 Nov 19. URL: <https://www.businessinsider.com/instagram-removing-likes-what-it-will-look-like-2019-11> [accessed 2020-03-23]
51. Lobstein T, Baur L, Uauy R. Obesity in children and young people: a crisis in public health. *Obesity Rev* 2004 May;5(s1):4-85. [doi: [10.1111/j.1467-789x.2004.00133.x](https://doi.org/10.1111/j.1467-789x.2004.00133.x)]
52. Wilcox BL, Kunkel D, Cantor J, Dorwick P, Linn S, Palmer E. Report of the APA Task Force on Advertising and Children. American Psychological Association. 2004. URL: <https://www.apa.org/pi/families/resources/advertising-children.pdf> [accessed 2020-03-24]
53. Chernin A. The Effects of Food Marketing on Children's Preferences: Testing the Moderating Roles of Age and Gender. *Ann Am Acad Pol Soc Sci* 2008 Jan;615(1):101-118. [doi: [10.1177/0002716207308952](https://doi.org/10.1177/0002716207308952)]
54. Radesky J, Chassiakos YLR, Ameenuddin N, Navsaria D, Council on Communication and Media. Digital Advertising to Children. *Pediatrics* 2020 Jul;146(1):e20201681 [FREE Full text] [doi: [10.1542/peds.2020-1681](https://doi.org/10.1542/peds.2020-1681)] [Medline: [32571990](https://pubmed.ncbi.nlm.nih.gov/32571990/)]

Abbreviations

COPPA: Children's Online Privacy and Protection Act

Edited by G Eysenbach; submitted 16.05.20; peer-reviewed by C Holmberg, N Levitz; comments to author 21.06.20; revised version received 11.07.20; accepted 19.07.20; published 27.10.20.

Please cite as:

Lutfeali S, Ward T, Greene T, Arshonsky J, Seixas A, Dalton M, Bragg MA

Understanding the Extent of Adolescents' Willingness to Engage With Food and Beverage Companies' Instagram Accounts: Experimental Survey Study

JMIR Public Health Surveill 2020;6(4):e20336

URL: <https://publichealth.jmir.org/2020/4/e20336>

doi: [10.2196/20336](https://doi.org/10.2196/20336)

PMID: [33107836](https://pubmed.ncbi.nlm.nih.gov/33107836/)

©Samina Lutfeali, Tisheya Ward, Tenay Greene, Josh Arshonsky, Azizi Seixas, Madeline Dalton, Marie A Bragg. Originally published in JMIR Public Health and Surveillance (<http://publichealth.jmir.org>), 27.10.2020. This is an open-access article distributed under the terms of the Creative Commons Attribution License (<https://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in JMIR Public Health and Surveillance, is properly cited. The complete bibliographic information, a link to the original publication on <http://publichealth.jmir.org>, as well as this copyright and license information must be included.

Original Paper

Independent and Combined Associations of Physical Activity, Sedentary Time, and Activity Intensities With Perceived Stress Among University Students: Internet-Based Cross-Sectional Study

Shu Ling Tan^{1*}, PhD; Malte Jetzke^{1*}, PhD; Vera Vergeld^{2*}, PhD; Carsten Müller^{3,4*}, PhD

¹Department for Social Sciences of Sport, Institute for Sport and Exercise Science, University of Münster, Münster, Germany

²Department of Sport and Exercise Psychology, Institute for Sport and Exercise Science, University of Münster, Münster, Germany

³University Sports, University of Münster, Münster, Germany

⁴Department of Physical Therapy, European University of Applied Sciences, Cologne (Köln), Germany

* all authors contributed equally

Corresponding Author:

Shu Ling Tan, PhD

Department for Social Sciences of Sport

Institute for Sport and Exercise Science

University of Münster

Horstmarer Landweg 62a

Münster

Germany

Phone: 49 025 1833 2175

Email: shuling.tan@uni-muenster.de

Abstract

Background: Mental health is an emerging topic on university campuses, with students reporting higher levels of psychological distress than the general population of the same age. Increasing physical activity and reducing sedentary time have been proved promising measures to promote mental health in the general population. However, to derive and implement effective measures to promote mental health among university students, further exploration of the associations between physical activity, sedentary time, and perceived stress in this specific setting is needed.

Objective: This study aims to identify associations between physical activity, sedentary time, and perceived stress after controlling for sociodemographic and behavioral variables among university students in Germany. We hypothesize that perceived stress is inversely related to physical activity and positively associated with sedentary time. Furthermore, we hypothesize that combined associations of concurrently high physical activity and low sedentary time on perceived stress are stronger compared with either alone and that the association between physical activity and perceived stress depends on activity intensity.

Methods: We conducted cross-sectional analyses from a large-scale internet-based student health survey (n=4189; response rate=10.0%). Physical activity, sedentary time, and engaging in moderate and vigorous activity intensities were assessed using the International Physical Activity Questionnaire Short Form with categorization into low, intermediate, and high levels. We measured perceived stress using the 10-item Perceived Stress Scale (range 0-40).

Results: The results indicate that higher physical activity and lower sedentary time are associated with reduced levels of perceived stress. Following adjustment for gender, BMI, income, fruit and vegetable intake, alcohol consumption, and sleep quality, perceived stress scores were lower for students reporting high physical activity levels and low sedentary time compared with the least active and highly sedentary students (Perceived Stress Scale -2.2, 95% CI -2.9 to -1.5, $P<.001$ for physical activity and -1.1, CI 95% -1.7 to -0.5, $P<.001$ for sedentary time). Combined associations with perceived stress revealed that students concurrently reporting high total physical activity and low sedentary time reported the lowest perceived stress scores of all possible combinations following adjustment for confounders (Perceived Stress Scale -3.5, CI 95% -4.6 to -2.5, $P<.001$ compared with students reporting low physical activity levels and concurrently high sedentary time). Associations between vigorous physical activities and perceived stress were not stronger compared with moderate activity intensities.

Conclusions: Self-reported physical activity and low sedentary time are favorably associated with perceived stress, while the intensity of physical activities seems to be of minor importance. These results help to effectively implement health-promoting measures on campus among university students through increasing physical activity and reducing sedentary time.

KEYWORDS

physical activity; sedentary time; intensity of physical activity; perceived stress; university students; internet-based cross-sectional study; independent associations; combined associations

Introduction

Background

Insufficient physical activity (PA) with increased sedentary time (ST) and stress are major problems among young adults. Globally, 1 in 4 adults does not meet the recommendations on PA for health [1]. Several reasons for being insufficiently physically active during the transition into adulthood and especially during university years have been proposed such as lack of time or social support; stress and tiredness attributable to study overload; and structural barriers like homework, class schedules, and overcrowded facilities [2,3]. With the increased use of technology, young adults tend to be less physically active and exhibit extensive sitting times [1,4]. Additionally, major life changes might also contribute to a decline in PA that potentially impact the level of perceived stress among students, like living away from home and adjusting to a new social environment, experiencing financial difficulties, and maintaining high levels of academic achievement [5,6].

Previous studies indicate a substantial decrease in PA during the transition from late adolescence into adulthood [7] and about half of university students in Western countries are not sufficiently active to gain health benefits [8-10]. Furthermore, according to self-reports, university students spend about 7½ hours per day being sedentary, putting them at increased risk for detrimental health outcomes [11]. This is worrying given the fact that PA habits are likely to be established in young adulthood and persist throughout life [12]. This behavioral change is of particular importance because the lack of PA is one of the top 3 modifiable risk factors of chronic disease and premature death at a later age [1,13].

Perceived Stress Among University Students

University students, particularly female students, appear to experience greater psychological distress [14,15] and higher levels of depression and anxiety [16,17] than the general population. Recent national data from one of the main health insurance providers in Germany indicate that 25% of the university students show symptoms of burnout and report doubts regarding their chosen study program. Moreover, 15.6% report symptoms of poor mental health and depression, and 17.4% report symptoms of a generalized anxiety disorder [18].

High levels of perceived stress have consistently been attributed to academic and social stressors within the university setting, such as academic workload [19], interpersonal relationships [20], and the transition to living independently [21]. Interestingly, students engaging in multiple health risk behaviors, such as physical inactivity, smoking, and unhealthy diet, reported the poorest mental health, particularly as it relates to stress [22].

Associations of Physical Activity, Sedentary Time, and Perceived Stress

Overall Physical Activity and Perceived Stress

Previous reviews analyzing evidence from cross-sectional, prospective, and experimental studies have demonstrated that PA has potential to reduce perceived stress [23,24]. Various neurobiological pathways and psychosocial factors have been discussed to theoretically explain the association of PA and mental health in general and particularly on stress. Accordingly, PA is often recommended as a strategy for managing stress in adult populations [25]. However, according to a recent systematic review, a research gap still exists regarding the association of PA with stress among university students [26]. The few studies examining the relationship between PA or exercise and mental health among university students suggest that higher PA, particularly aerobic activity, is associated with lower levels of perceived stress [27,28]. Similarly, a study examining low, intermediate, and high PA groups and associations with anxiety and depression scales found that higher activity levels were associated with better self-reported mental health [29]. In addition, studies discovered positive relationships between PA and self-rated quality of life [30] and inverse associations between PA and perceived stress [31].

Sedentary Time and Perceived Stress

Increased use of technology is one of the main reasons for not meeting the recommended level of PA for health [1]. Students' sedentary behavior steadily increases due to the growing use of multiple mobile devices used for studying, staying in touch with family and friends, playing computer games, and watching television [4]. These screen-based activities are strongly associated with sedentary behavior and stress, and thus, ST has been suggested as an independent predictor of metabolic risk and mental health outcomes [32], with inflammatory responses and psychosocial mechanisms being likely pathways to explain this association [28,33,34]. A few studies examined the relationship of ST with stress among university students with contradictory findings: while high ST was associated with high levels of perceived stress [35,36], recently published device-based data indicate that only leisure-time sedentary behavior, but not total ST, was associated with perceived stress [28]. Hitherto, only one study examined combined associations between PA, ST, and perceived stress and found significant combined associations in female but not in male university students [36].

Activity Intensity and Perceived Stress

Apart from the total volume of PA, it has recently been proposed that the activity intensity might mediate the association of PA and mental health. Research investigating the differential effects of vigorous PA (vPA) and moderate PA (mPA) on perceived stress among university students is scarce and equivocal. For

instance, Gerber et al [37] examined whether vPA provides additional mental health benefits beyond mPA. In fact, their results show that vPA was associated with decreased perceived stress, pain, subjective sleep complaints, and depressive symptoms. These findings are supported by previous studies on stress, anxiety, and depression among the general population [38,39]. Contrarily, Paolucci et al [40] demonstrated that vPA (high-intensity interval training) evoked increased levels of perceived stress, and mPA might represent an optimal activity intensity for the promotion of mental health among university students.

Hypotheses

Although the associations between PA and stress have been investigated previously among adults and college students, studies among university students are scarce and partly contradictory. To derive and implement appropriate health promotion measures in the university setting, the associations between PA, ST, and perceived stress needs further examination. Based on current literature, we hypothesize the following:

- Perceived stress is inversely related to overall PA and positively associated with ST
- The combined association of PA and ST with perceived stress is stronger than the associations of either variable alone
- The association between PA and perceived stress depends on the intensity of PA, and this relationship is stronger for vPA compared with mPA

Methods

Study Design and Setting

This study adhered to the Checklist for Reporting Results of Internet E-Surveys (CHERRIES) guidelines (Multimedia Appendix 1) [41]. A cross-sectional online study was implemented at the University of Münster in Germany. Ethical approval was obtained from the university institutional review board. The health survey was completed during the summer term in year 2019. All regular university students were eligible to take part in this internet-based health survey except cross-registered students, auditing students, and senior citizen students. The remaining 42,630 students were invited by email to take part. We offered the questionnaire in German and English languages to provide international students the opportunity to participate. Students received an invitation email and were provided with an individual transaction number. The email included information on the length of the survey (20 to 30 minutes, 172 items on 15 pages), voluntariness, anonymity, data protection, and incentives (eg, a chance to win VIP tickets for sporting events). Students not replying to the invitation were reminded twice within 2 weeks to take part. Prior to the online survey, all participants gave informed consent.

The survey was administered without randomization of items using the evaluation software EvaSys version 8.0 with adaptive questioning (Electric Paper Evaluationssysteme GmbH). Students were able to change their answers by using a back button. No completeness check was available. However, incomplete surveys were captured as well.

Measurements

Physical Activity

Students' PA levels and total ST were assessed using the International Physical Activity Questionnaire Short Form (IPAQ-SF) [42]. This questionnaire included 7 questions to assess vPA, mPA, walking, and ST related to the previous week by asking for frequency (days per week) and duration (minutes per day). Valid answers require PA durations of at least 10 minutes but no more than 180 minutes in each category, allowing for calculating weekly MET (metabolic equivalent of task) minutes. Vigorous MET minutes per week are calculated by multiplying the product of frequency and duration with the factor 8. Moderate and walking MET minutes are obtained using the factors 4 and 3.3, respectively. ST was assessed with a single question about the average daily ST in hours during the previous week. Missing PA or ST data were considered as completely missing for this case and not considered for statistical analysis (n=80). The IPAQ-SF has acceptable measurement properties, as demonstrated in adult populations showing adequate criterion validity against accelerometry (Spearman ρ =-.30, CI 95% .23 to .36) and acceptable test-retest reliability (ρ =-.76, CI 95% .73 to .77) [42]. Furthermore, the IPAQ-SF demonstrates reasonable validity in university students with Pearson r ranging from .27 to .70 when compared with accelerometer counts and mPA to vPA uniaxial and triaxial cut points [43].

Perceived Stress

The Perceived Stress Scale (PSS) [44] is a widely used 10-item self-report scale representing a reliable, valid, and economic instrument for assessing perceived stress [45]. Students responded on a 5-point Likert scale ranging from 0 = never to 4 = very often to the degree they appraised life situations as overwhelming, unpredictable, and uncontrollable (eg, In the last month, how often have you been upset because of something that happened unexpectedly?). After recoding the positively stated items 4, 5, 7, and 8, a total score is obtained by summing all 10 items to a PSS score ranging between 0 to 40. Higher scores indicate increased levels of perceived stress, but there are no predefined cutoffs. Ipsative mean imputation was used (n=70) when not more than 1 item of the complete scale was missing. In case of 2 or more missing items, the subject was not considered for statistical analysis (n=14). In this study, internal consistency was good to excellent with Cronbach alpha=.88.

Potential Confounders

Several sociodemographic and behavioral factors were considered a priori as potential confounding variables. Sociodemographic confounders encompass gender (dichotomized), BMI (kg/m²), total number of semesters studied, and income categorized into 5 levels: <450 EUR, 450-699 EUR, 700-949 EUR, 950-1150 EUR, and >1150 EUR. Behavioral confounders include current smoking status (dichotomized), alcohol use, sleep quality, and fruit and vegetable intake categorized into 4 levels: no servings per day, 1 to 2 servings per day, 3 to 4 servings per day, and ≥ 5 servings per day (equivalent to the current nutrition recommendation). Alcohol consumption was assessed using the Alcohol Use Disorders

Identification Test for Consumption (AUDIT-C), a 3-item questionnaire that is recommended as a short and valid screening for hazardous drinking among university students [46]. Sleep quality was assessed using the short-form Pittsburgh Sleep Quality Index (sPSQI), a 13-item questionnaire assessing sleep quality over a 4-week time interval that demonstrates high agreement with the original 19-item survey [47].

Data Reduction

PA data were analyzed according to the Guidelines for Data Processing and Analysis of the International Physical Activity Questionnaire [48], resulting in 3 levels of total PA. A high PA level requires vigorous intensity activity on at least 3 days and accumulating at least 1500 MET minutes per week or a combination of walking, mPA, and/or vPA accumulating at least 3000 MET minutes per week. The level of PA is classified as intermediate with either 3 or more days of vPA of at least 20 minutes per day, 5 or more days of mPA and/or walking of at least 30 minutes per day, or accumulating at least 600 MET minutes per week of any combination of walking, mPA, or vPA. All individuals not meeting these criteria are considered to have a low PA level. ST was categorized according to previous studies in <6 hours per day, 6 to 8 hours per day, and >8 hours per day for low, intermediate, and high levels of ST, respectively [49-51].

Average MET scores are derived for the different intensities of PA (ie, mPA = 4 METs and vPA = 8 METs). Based on these values we categorized mPA and vPA into 3 different levels based on the above mentioned classification of high PA levels: a high level of vPA requires the accumulation of ≥ 1500 MET minutes per week of vPA, while an intermediate level is achieved by accumulating 600 to 1499 MET minutes per week of vPA. Individuals not meeting the above criteria were categorized as having a low level of vPA. Accordingly, accumulating ≥ 750 MET minutes, 300 to 749 MET minutes, and <300 MET minutes of mPA resulted in high, intermediate, and low levels of mPA, respectively.

Statistical Analysis

Descriptive statistics include mean and standard deviation. Gender differences for dependent and independent variables were analyzed using chi-square tests for ordinal data and multivariate analysis of variance with Bonferroni adjustments for continuous variables. We used generalized linear models to assess combined associations for PA by ST interaction with

perceived stress and to assess the association between different activity intensity levels (ie, vPA by mPA interaction) and perceived stress using linear regression models with robust estimator covariance matrix. We categorized exposure data (PA level and ST) into 3 groups, with the first level (lowest total PA and highest ST) as reference. Combined associations between PA and perceived stress were analyzed without any adjustments (model A), with adjustments for sociodemographic variables (model B), and with additional adjustments for behavioral factors (model C). The results are presented as regression coefficient B with Wald 95% confidence intervals. Independent associations between PA variables and perceived stress are presented as unstandardized (B) and standardized regression coefficients (β) and were analyzed using fully adjusted generalized linear regression models and pairwise comparisons with Bonferroni adjustments. The level of statistical significance was set at $P < .05$. All analyses were performed using SPSS Statistics version 26 (IBM Corp).

Results

Participants and Descriptive Data

In all, 4189 students participated in this online survey, resulting in an overall response rate of 10.0% (4189/42,630, range 7.2% to 22.1% among the 21 university departments). A total of 67.8% (2840/4189) were female. Participant characteristics by gender are summarized in Table 1. Results of a multivariate analysis of variance indicated significant gender differences in perceived stress and sociodemographic and behavioral variables ($F_{5, 3967} = 67.58$, $P < .001$, $\eta^2 = .08$). Particularly, females reported higher perceived stress (mean 20.0 [SD 6.9]) compared with male students (mean 17.6 [SD 7.2]; $F_{1, 3971} = 95.72$, $P < .001$, $\eta^2 = .02$). No gender differences were found for ST ($\chi^2_{2, N=4121} = 4.70$, $P = .095$). However, female students were more likely to report intermediate PA levels (1348/2795, 48.2%), whereas male students were more likely to report low (156/1325, 11.8%) and high (614/1326, 46.3%) PA levels ($\chi^2_{2, N=4120} = 23.75$, $P < .001$). Male students were more likely to report engaging in high amounts of vPA ($\chi^2_{2, N=4120} = 16.64$, $P < .001$). Gender, income, fruit and vegetable intake, alcohol consumption, sleep quality (all $P < .001$), and BMI ($P = .02$) were significant covariates and explained 23.0% of the variance in perceived stress ($F_{6, 3942} = 197.10$, $P < .001$).

Table 1. Characteristics of university students by gender.

Characteristic	Total (n=4189)	Female (n=2840)	Male (n=1349)	P value
Age in years, mean (SD)	23.7 (4.3)	23.4 (3.9)	24.4 (5.0)	<.001 ^a
BMI, mean (SD)	22.8 (3.8)	22.3 (3.9)	23.7 (3.6)	<.001 ^a
Number of semesters, mean (SD)	8.4 (5.5)	8.1 (4.9)	9.3 (6.5)	<.001 ^a
Income (EUR), n (%)	— ^b	—	—	<.001 ^c
<450	863 (18.4)	531 (18.9)	232 (17.3)	
450-699	1273 (30.6)	907 (32.2)	366 (27.3)	
700-949	1120 (27.0)	776 (27.6)	344 (25.7)	
950-1150	464 (11.2)	302 (10.7)	162 (12.1)	
>1150	534 (12.9)	299 (10.6)	235 (17.6)	
Current smoker, n (%)	379 (9.4)	215 (7.8)	164 (12.7)	<.001 ^c
FVI^d, n (%)	—	—	—	<.001 ^c
0 servings per day	64 (1.6)	24 (0.9)	40 (3.1)	
1-2 servings per day	2094 (52.0)	1269 (46.2)	825 (64.2)	
3-4 servings per day	1552 (38.5)	1216 (44.3)	336 (26.1)	
≥5 servings per day	319 (7.9)	235 (8.6)	319 (6.5)	
AUDIT-C ^e , mean (SD)	3.5 (2.3)	3.2 (2.1)	4.0 (2.6)	<.001 ^a
sPSQI ^f , mean (SD)	4.6 (2.2)	4.7 (2.2)	4.4 (2.1)	<.001 ^a
PA^g class, n (%)	—	—	—	<.001 ^c
Low	377 (9.2)	221 (7.9)	156 (11.8)	
Intermediate	1903 (46.2)	1348 (48.2)	555 (41.9)	
High	1840 (44.7)	1226 (43.9)	614 (46.3)	
ST^h class, n (%)	—	—	—	.095 ^c
Low	663 (16.1)	472 (16.9)	191 (14.4)	
Intermediate	1650 (40.0)	1119 (40.0)	531 (40.0)	
High	1808 (43.9)	1204 (43.1)	604 (45.6)	
vPAⁱ class, n (%)	—	—	—	<.001 ^c
Low	1735 (42.1)	1209 (43.3)	526 (39.7)	
Intermediate	1379 (33.5)	956 (34.2)	423 (31.9)	
High	1006 (24.4)	630 (22.5)	376 (28.4)	
mPA^j class, n (%)	—	—	—	.027 ^c
Low	1248 (30.3)	815 (29.2)	433 (32.7)	
Intermediate	1595 (38.7)	1117 (40.0)	478 (36.1)	
High	1277 (31.0)	863 (30.9)	414 (31.2)	
PSS ^k score, mean (SD)	19.2 (7.1)	20.0 (6.9)	17.6 (7.2)	<.001 ^a

^aMANOVA: multivariate analysis of variance.

^bNot applicable.

^cChi-square.

^dFVI: fruit and vegetable intake.

^eAUDIT-C: Alcohol Use Disorders Identification Test for Consumption.

^fsPSQI: short Pittsburgh Sleep Quality Index.

^gPA: physical activity.

^hST: sedentary time.

ⁱvPA: vigorous physical activity.

^jmPA: moderate physical activity.

^kPSS: Perceived Stress Scale.

Independent Associations of Physical Activity and Sedentary Time With Perceived Stress

Generalized linear regression models were performed to analyze independent associations between perceived stress and PA variables after adjusting for covariates (Table 2). The strongest associations with perceived stress were found for total PA. Consistently, higher PA levels ($P<.001$), lower ST ($P<.001$), and higher engagement in mPA and vPA ($P\leq.01$) were associated with lower perceived stress. Highly active students

report -0.7 (CI 95% -1.2 to -0.2 , $P=.003$) and -2.2 (CI 95% -3.1 to -1.3 , $P<.001$) lower mean perceived stress scores compared with students categorized as intermediate and low physically active, while students in the intermediate PA category report -1.5 (CI 95% -2.4 to -0.6 , $P<.001$) lower mean perceived stress scores compared with students categorized as least physically active. A comparable trend with weaker associations was found for ST with the exception that low and intermediate ST groups did not differ in perceived stress scores, with a mean difference of -0.1 (CI 95% -0.8 to 0.6 , $P>.99$).

Table 2. Independent associations of physical activity levels, sedentary time, and perceived stress^a.

Characteristic	Perceived stress			
	Mean (95% CI)	B ^b (95% CI)	P value	β^c (95% CI)
PA^d level				
Low	20.8 (20.1 to 21.5)	0 (reference)	—	1 (reference)
Intermediate	19.2 (18.9 to 19.5)	-1.53 (-2.28 to -0.79)	$<.001$	0.22 (0.10 to 0.45)
High	18.6 (18.3 to 18.9)	-2.21 (-2.96 to -1.46)	$<.001$	0.11 (0.05 to 0.23)
ST^e level				
Low	20.2 (19.9 to 20.6)	0 (reference)	—	1 (reference)
Intermediate	19.2 (18.9 to 19.6)	-0.99 (-1.41 to -0.56)	$<.001$	0.37 (0.25 to 0.57)
High	19.1 (18.6 to 19.6)	-1.10 (-1.66 to -0.54)	$<.001$	0.33 (0.19 to 0.58)
vPA^f level				
Low	19.6 (19.3 to 19.9)	0 (reference)	—	1 (reference)
Intermediate	19.0 (18.7 to 19.3)	-0.62 (-1.08 to -0.17)	$.007$	0.54 (0.34 to 0.84)
High	18.8 (18.4 to 19.2)	-0.86 (-1.38 to -0.34)	$.001$	0.42 (0.25 to 0.71)
mPA^g level				
Low	19.7 (19.3 to 20.1)	0 (reference)	—	1 (reference)
Intermediate	19.1 (18.8 to 19.4)	-0.61 (-1.09 to -0.14)	$.011$	0.54 (0.34 to 0.87)
High	18.6 (18.2 to 18.9)	-1.11 (-1.63 to -0.60)	$<.001$	0.33 (0.20 to 0.55)

^aRegression model adjusted for gender, BMI, income, fruit and vegetable intake, alcohol consumption, and sleep quality.

^bB: unstandardized regression coefficient.

^c β : standardized regression coefficient.

^dPA: physical activity.

^eST: sedentary time.

^fvPA: vigorous physical activity.

^gmPA: moderate physical activity.

Pairwise comparisons indicate that associations with perceived stress were similar for engaging in vPA and mPA when comparing the intermediate with the low physically active group (vPA -0.6 [CI 95% -1.2 to -0.1 , $P=.02$], mPA -0.6 [CI 95% -1.2 to 0 , $P=.03$]). The comparison of high versus intermediate and high versus low engagement in both activity intensity categories indicates a stronger association for mPA with perceived stress compared with vPA and stress (vPA high vs

intermediate -0.2 [CI 95% -0.9 to 0.4 , $P>.99$] and mPA high vs intermediate -0.5 [CI 95% -1.1 to 0.1 , $P=.11$]; vPA high vs low -0.9 [CI 95% -1.5 to -0.2 , $P=.004$] and mPA high vs low -1.1 (CI 95% -1.7 to -0.5 , $P<.001$)).

Combined Associations With Perceived Stress

Generalized linear regression models with interaction effects examined the combined association of PA by ST with perceived

stress (Table 3), as well as of vPA by mPA with perceived stress (Table 4). Analyses include an unadjusted model (model A), a model adjusted for sociodemographic factors (model B), and a model additionally adjusted for behavioral factors (model C).

All models consistently indicate that higher total PA and lower ST are associated with reduced perceived stress scores. The interaction of total PA and ST also reveals that for the least active students, the transition from a high to an intermediate and from a high to a low ST is associated with mean perceived stress score reductions of -1.3 ($P=.14$) to -1.4 ($P=.07$) and -2.2 ($P=.045$) to -2.7 ($P=.02$), respectively. Contrarily, these

transitions are minor for students categorized as intermediately physically active and marginal for the most active students (Table 3).

The combined analysis of vPA and mPA indicates consistent inverse associations with perceived stress (Table 4). Students engaging in high amounts of vPA and high amounts of mPA revealed the strongest associations with perceived stress with significantly lower scores ranging from -3.6 in the unadjusted model to -2.1 in the fully adjusted model (each $P<.001$) compared with students in the reference group.

Table 3. Combined associations of physical activity levels and sedentary time on perceived stress.

PA ^a and ST ^b levels	Perceived stress					
	Model A ^c (n=4072), B (95% CI)	P value	Model B ^d (n=4017), B (95% CI)	P value	Model C ^e (n=3945), B (95% CI)	P value
Low						
High	0 (reference)		0 (reference)		0 (reference)	
Intermediate	-1.26 (-2.94 to 0.42)	.14	-1.32 (-2.97 to 0.33)	.12	-1.40 (-2.91 to 0.10)	.07
Low	-2.46 (-4.69 to -0.22)	.03	-2.71 (-4.92 to -0.50)	.02	-2.16 (-4.27 to -0.05)	.045
Intermediate						
High	-1.66 (-2.73 to -0.58)	.003	-1.95 (-3.02 to -0.88)	<.001	-1.74 (-2.74 to -0.75)	.001
Intermediate	-3.07 (-4.14 to -1.99)	<.001	-3.39 (-4.46 to -2.32)	<.001	-2.80 (-3.80 to -1.81)	<.001
Low	-3.53 (-4.80 to -2.26)	<.001	-3.94 (-5.19 to -2.69)	<.001	-2.78 (-3.95 to -1.62)	<.001
High						
High	-2.79 (-3.89 to -1.69)	<.001	-3.02 (-4.11 to -1.93)	<.001	-2.54 (-3.55 to -1.53)	<.001
Intermediate	-4.15 (-5.23 to -3.07)	<.001	-4.24 (-5.31 to -3.17)	<.001	-3.35 (-4.36 to -2.34)	<.001
Low	-4.16 (-5.37 to -2.94)	<.001	-4.46 (-5.67 to -3.26)	<.001	-3.51 (-4.62 to -2.39)	<.001

^aPA: physical activity.

^bST: sedentary time.

^cModel A: unadjusted regression model.

^dModel B: regression model adjusted for sociodemographic variables (sex, BMI, income).

^eModel C: regression model adjusted for sociodemographic and behavioral variables (model B plus fruit and vegetable intake, alcohol use, and sleep quality).

Table 4. Combined associations of vigorous and moderate physical activity on perceived stress.

vPA ^a and mPA ^b levels	Perceived stress					
	Model A ^c (n=4072), B (95% CI)	P value	Model B ^d (n=4017), B (95% CI)	P value	Model C ^e (n=3945), B (95% CI)	P value
Low						
Low	0 (reference)	—	0 (reference)	—	0 (reference)	—
Intermediate	-1.27 (-2.05 to -0.49)	.001	-1.41 (-2.17 to -0.64)	<.001	-0.88 (-1.58 to -0.19)	.01
High	-2.45 (-3.34 to -1.57)	<.001	-2.33 (-3.21 to -1.46)	<.001	-1.63 (-2.46 to -0.80)	<.001
Intermediate						
Low	-2.07 (-2.93 to -1.22)	<.001	-2.03 (-2.87 to -1.19)	<.001	-1.35 (-2.13 to -0.58)	.001
Intermediate	-2.12 (-2.89 to -1.35)	<.001	-2.06 (-2.82 to -1.30)	<.001	-1.23 (-1.93 to -0.53)	.001
High	-2.67 (-3.51 to -1.83)	<.001	-2.67 (-3.50 to -1.83)	<.001	-1.81 (-2.58 to -1.05)	<.001
High						
Low	-1.93 (-3.13 to -0.72)	.002	-1.58 (-2.76 to -0.40)	.009	-0.82 (-1.88 to 0.24)	.13
Intermediate	-2.85 (-3.76 to -1.95)	<.001	-2.80 (-3.70 to -1.90)	<.001	-1.97 (-2.80 to -1.14)	<.001
High	-3.55 (-4.39 to -2.71)	<.001	-3.35 (-4.18 to -2.53)	<.001	-2.08 (-2.83 to -1.33)	<.001

^avPA: vigorous physical activity.

^bmPA: moderate physical activity.

^cModel A: unadjusted regression model.

^dModel B: regression model adjusted for sociodemographic variables (sex, BMI, income).

^eModel C: regression model adjusted for sociodemographic and behavioral variables (model B plus fruit and vegetable intake, alcohol use, and sleep quality).

Discussion

Principal Findings

This study examined the associations of overall PA, ST, and activity intensity with perceived stress among university students. In line with previous studies, female students report higher levels of perceived stress compared with male students. As hypothesized, perceived stress is inversely related to the amount of PA and positively associated with ST. Our results further indicate that the combined associations of PA and ST with perceived stress are stronger than compared with either alone. However, contrary to our last hypothesis, engaging in vPA did not reveal stronger associations with perceived stress compared with engaging in mPA.

Associations of Physical Activity, Sedentary Time, and Perceived Stress

In our first hypothesis, we assumed that self-reported PA and ST are independently associated with perceived stress. For total PA, we were able to demonstrate a dose-response relationship with perceived stress, confirming our hypothesis that a higher level of overall PA is inversely associated with perceived stress, which is in line with previous studies among university students [27,52,53]. Several reasons may explain these associations from different perspectives. Presumably, there is no single mechanism that can explain this relationship on its own. Beneficial effects of PA on stress have been demonstrated including physiological mechanisms (eg, increased endorphin levels, body temperature, neurotransmitter secretion), cognitive behavioral effects (eg, distraction from negative feelings, mastery, self-efficacy), and

inflammatory mechanisms (eg, cytokine release, reduction of visceral fat mass, increase in vagal tone) [23,54].

According to our categorization into low, intermediate, and high ST, which was based on previous epidemiological studies [51,55], our findings generally support preceding research indicating that ST among university students is positively associated with perceived stress [28,35,36]. However, our findings do not support the notion of a clear dose-response relationship. Though students in the high ST category reported the highest stress levels, students in the low or intermediate ST category revealed only negligible differences in perceived stress. This is partly in line with the only study among university students we are aware of examining the association between self-reported ST and perceived stress [28]. In their study, Felez-Nobrega et al [28] demonstrated that ST was significantly related to perceived stress on weekends and during leisure time on weekdays but not associated with total ST on weekdays. Unfortunately, we were not able to differentiate between domain-specific PA and ST, as evidence grows that contextual factors matter in the effect of PA and ST on mental health [28,56,57]. It is likely that the lack of a clear dose-response relationship between ST and perceived stress in our study might be ascribed to a too narrow categorization of ST level (<6 hours, 6 to 8 hours, >8 hours) and/or the lack of considering domain-specific ST.

Combined Associations of Physical Activity and Sedentary Time With Perceived Stress

These results confirm our second hypothesis that the combined associations of PA and ST with perceived stress are stronger

compared with either PA or ST alone. Acknowledging that studies on combined effects of PA and ST among university students are rare, this constitutes a starting point for future research. However, in line with a recent study among college students [36], the odds for experiencing increased perceived stress were lowest when students engaged in high levels of PA and low levels of ST. Similarly, the combination of insufficient PA and smartphone use, a correlate of ST, revealed stronger associations with high levels of perceived stress compared with only one or none of these health risk behaviors [58]. These current findings further support the notion of a dose-response relationship between the combinations of PA and ST and perceived stress. The results indicate that reducing ST and increasing PA both seem promising approaches for university mental health promotion programs. These scenarios could find their rationale in the observation that university students engage in high volumes of ST due to activities like attending lectures and studying that potentially place them at detrimental physical [49] and mental health states [59,60].

Associations of Physical Activity Intensity and Perceived Stress

In our third hypothesis, we supposed that the association between PA and perceived stress was stronger for engaging in vPA compared with mPA. However, our results do not support this assumption. Intermediate compared with low engagement in mPA and vPA did not reveal different associations with perceived stress. However, the results indicate that high engagement in mPA is associated with marginally lower perceived stress compared with high engagement in vPA. Although this result does not challenge the finding that vPA has a stress protective potential among undergraduate students with high stress levels [52,61], it contradicts results from previous studies indicating that vPA is associated with mental health benefits beyond mPA [37]. In their study, Gerber et al [62] analyzed a convenience sample of 42 university students but implemented device-based PA assessments, representing a strength of their study, given that self-reports tend to overestimate PA due to social desirability and recall bias. Thus, we assume that the dissimilar assessment methods and a more representative sample in our study might have impacted the divergent results. Although vPA certainly plays an important role in the association of PA and stress, very strenuous exercises like high-intensity interval training might induce adverse effects. Paolucci et al [40] argue that physiological responses to high-intensity exercise might exacerbate physiological responses to psychological stressors and increase perceptions of stress. This would suggest a U-shaped dose-response relationship for PA and stress with an upper activity intensity limit and mPA as the optimal activity intensity for beneficial effects on perceived stress among university students.

Interpretations and Generalizability

In general, findings of this study indicate that higher overall PA, lower ST, and high engagement in mPA and vPA are favorably associated with perceived stress among university students. These results corroborate previous research demonstrating that PA-related health behaviors, including higher

levels of mPA, vPA, and low ST, are associated with the lowest levels of stress, depression, and anxiety [28,63,64].

University students, particularly females, are highly vulnerable to higher levels of stress, depressive symptoms, and anxiety and poorer overall mental health than the general population [15,65-67]. This can be attributed to reasons like the transition into adulthood and major lifestyle changes related to their studies [5,14,15]. Given that impaired mental health predicts study dropouts, there is a clear need for mental health promotion measures, particularly among female students. University students also tend to be at risk for unhealthy behaviors [22], including insufficient PA and prolonged ST [35]. These may as well be related to the university setting that inevitably promotes sedentary behavior during lectures, while studying, or even during socializing. It is essential to identify effective ways to cope with stress in the university setting. Engaging in PA is one of the most popular and common ways to manage stress, and the findings of this study strengthen this hypothesis. Lifestyle habits that develop during university studies are likely to manifest and thus may affect future health [68]. This points to the necessity of implementing student health management including opportunities for reducing sedentary behavior and PA promotion on campus.

Strengths, Limitations, and Implications for Future Research

This is one of the few studies examining independent and combined associations of PA, ST, and activity intensity with perceived stress among university students. We recruited a representative sample size, covering all faculties of the university, and saw a response rate of 10%. The outcome variables and their categorization represent internationally accepted standards, and we were able to address sociodemographic and behavioral confounders in our analyses. In addition, we adopted the CHERRIES checklist to improve reporting results of online surveys. However, the results must be interpreted considering the following limitations. First, participants were recruited from a single university in Germany, limiting the generalizability of the results. Second, the cross-sectional study design does not allow for causal inferences. Given that being physically active has beneficial effects on perceived stress through neurophysiological, psychosocial, and behavioral mechanisms, we do not neglect the notion that high levels of perceived stress might also impact ST and PA behavior, which suggests a bidirectional association. To examine cause-effect relationships, prospective experimental study designs must be considered. Using self-reports is inherently subjected to bias, predisposing to under- or overestimations of actual behavior. Although this study was careful in the selection of questionnaires, device-based assessments of PA using wearables, at least in subsamples, might be alternatives for future studies to provide more accurate outcomes and more detailed information. Last, given the scope of this large-scale health survey that covered many items on student health behavior, no differentiation of domain-specific PA or ST was feasible, but is encouraged for future studies to better derive tailored health-promoting measures in the university setting.

Conclusions

These findings indicate that total PA, low ST, and activity intensity are favorably associated with perceived stress among university students. The total volume of PA and ST and a moderate PA intensity influence the association with perceived stress and should be considered when developing student health promotion programs. In a sedentary university setting, where students are prone to prolonged ST, appropriate measures should

be taken to enable students to maintain sufficient levels of PA for optimal health and well-being. These could encompass a PA-friendly environment, education and measures aiming to promote PA (eg, taking stairs instead of elevators), active lecture breaks, and university sports offerings. Assuming a bidirectional association between PA, ST, and perceived stress, these measures should include stress management strategies to help students adhere to an active lifestyle in stressful periods as well.

Authors' Contributions

All authors contributed to this paper. SLT drafted parts of the manuscript and contributed to data analysis and interpretation. MJ contributed to data analysis and interpretation and manuscript writing. VV drafted parts of the manuscript and contributed to data analysis. CM conceived the study, collected data, performed data analysis, contributed to data interpretation, and drafted parts of the manuscript. All authors approved the final version of the manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Checklist for Reporting Results of Internet E-Surveys (CHERRIES).

[[PDF File \(Adobe PDF File\), 202 KB - publichealth_v6i4e20119_app1.pdf](#)]

References

1. Global action plan on physical activity 2018-2030: more active people for a healthier world. Geneva: World Health Organization; 2018. URL: <http://apps.who.int/iris/bitstream/handle/10665/272722/9789241514187-eng.pdf?ua=1> [accessed 2020-10-29]
2. Gómez-López M, Gallegos AG, Extremera AB. Perceived barriers by university students in the practice of physical activities. *J Sports Sci Med* 2010;9(3):374-381 [FREE Full text] [Medline: [24149629](#)]
3. Thomas AM, Beaudry KM, Gammage KL, Klentrou P, Josse AR. Physical activity, sport participation, and perceived barriers to engagement in first-year Canadian university students. *J Phys Act Health* 2019 Jun 01;16(6):437-446. [doi: [10.1123/jpah.2018-0198](#)] [Medline: [31130058](#)]
4. Alert MD, Saab PG, Llabre MM, McCalla JR. Are self-efficacy and weight perception associated with physical activity and sedentary behavior in Hispanic adolescents? *Health Educ Behav* 2018 Aug 17;46(1):53-62. [doi: [10.1177/1090198118788599](#)]
5. Van Dyck D, De Bourdeaudhuij I, Deliens T, Deforche B. Can changes in psychosocial factors and residency explain the decrease in physical activity during the transition from high school to college or university? *Int J Behav Med* 2015 Apr;22(2):178-186. [doi: [10.1007/s12529-014-9424-4](#)] [Medline: [25031186](#)]
6. Hamaideh SH. Stressors and reactions to stressors among university students. *Int J Soc Psychiatry* 2011 Jan;57(1):69-80. [doi: [10.1177/0020764009348442](#)] [Medline: [21252357](#)]
7. Corder K, Winpenney E, Love R, Brown HE, White M, Sluijs EV. Change in physical activity from adolescence to early adulthood: a systematic review and meta-analysis of longitudinal cohort studies. *Br J Sports Med* 2017 Jul 24;53(8):496-503. [doi: [10.1136/bjsports-2016-097330](#)] [Medline: [28739834](#)]
8. Irwin JD. Prevalence of university students' sufficient physical activity: a systematic review. *Percept Mot Skills* 2004 Jun;98(3 Pt 1):927-943. [doi: [10.2466/pms.98.3.927-943](#)] [Medline: [15209309](#)]
9. Romaguera D, Tauler P, Bannasar M, Pericas J, Moreno C, Martinez S, et al. Determinants and patterns of physical activity practice among Spanish university students. *J Sports Sci* 2011 Jun;29(9):989-997. [doi: [10.1080/02640414.2011.578149](#)] [Medline: [21590579](#)]
10. Clemente FM, Nikolaidis PT, Martins FML, Mendes RS. Physical activity patterns in university students: do they follow the public health guidelines? *PLoS One* 2016;11(3):e0152516 [FREE Full text] [doi: [10.1371/journal.pone.0152516](#)] [Medline: [27022993](#)]
11. Castro O, Bennie J, Vergeer I, Bosselut G, Biddle SJH. How sedentary are university students? A systematic review and meta-analysis. *Prev Sci* 2020 Apr;21(3):332-343. [doi: [10.1007/s1121-020-01093-8](#)] [Medline: [31975312](#)]
12. Gordon-Larsen P, Nelson MC, Popkin BM. Longitudinal physical activity and sedentary behavior trends: adolescence to adulthood. *Am J Prev Med* 2004 Nov;27(4):277-283. [doi: [10.1016/j.amepre.2004.07.006](#)] [Medline: [15488356](#)]
13. Muller DC, Murphy N, Johansson M, Ferrari P, Tsilidis KK, Boutron-Ruault M, et al. Modifiable causes of premature death in middle-age in Western Europe: results from the EPIC cohort study. *BMC Med* 2016 Jun 14;14:87 [FREE Full text] [doi: [10.1186/s12916-016-0630-6](#)] [Medline: [27296932](#)]

14. Ribeiro IJ, Pereira R, Freire IV, de Oliveira BG, Casotti CA, Boery EN. Stress and quality of life among university students: a systematic literature review. *Heal Prof Educ* 2018 Jun;4(2):70-77. [doi: [10.1016/j.hpe.2017.03.002](https://doi.org/10.1016/j.hpe.2017.03.002)]
15. Stallman H. Psychological distress in university students: a comparison with general population data. *Aust Psychol* 2011;45(4):249-257. [doi: [10.1080/00050067.2010.482109](https://doi.org/10.1080/00050067.2010.482109)]
16. Ibrahim AK, Kelly SJ, Adams CE, Glazebrook C. A systematic review of studies of depression prevalence in university students. *J Psychiatr Res* 2013 Mar;47(3):391-400. [doi: [10.1016/j.jpsychires.2012.11.015](https://doi.org/10.1016/j.jpsychires.2012.11.015)] [Medline: [23260171](https://pubmed.ncbi.nlm.nih.gov/23260171/)]
17. Dyrbye LN, Thomas MR, Shanafelt TD. Systematic review of depression, anxiety, and other indicators of psychological distress among U.S. and Canadian medical students. *Acad Med* 2006 Apr;81(4):354-373. [doi: [10.1097/00001888-200604000-00009](https://doi.org/10.1097/00001888-200604000-00009)] [Medline: [16565188](https://pubmed.ncbi.nlm.nih.gov/16565188/)]
18. Grutzmacher J, Gusy B, Lesener T, Sudheimer S, Willige J. Gesundheit Studierender in Deutschland 2017. Ein Kooperationsprojekt zwischen dem Deutschen Zentrum für Hochschul- und Wissenschaftsforschung, der Freien Universität Berlin und der Techniker Krankenkasse. URL: <https://www.tk.de/resource/blob/2050660/8bd39eab37ee133a2ec47e55e544abe7/gesundheitsstudierender-in-deutschland-2017-studienband-data.pdf> [accessed 2020-10-29]
19. Kausar R. Perceived stress, academic workloads and use of coping strategies by university students. *J Behav Sci* 2010;20(1):31 Corpus ID: 146778858.
20. Verger P, Combes J, Kovess-Masfety V, Choquet M, Guagliardo V, Rouillon F, et al. Psychological distress in first year university students: socioeconomic and academic stressors, mastery and social support in young men and women. *Soc Psychiatry Psychiatr Epidemiol* 2009 Aug;44(8):643-650. [doi: [10.1007/s00127-008-0486-y](https://doi.org/10.1007/s00127-008-0486-y)] [Medline: [19096741](https://pubmed.ncbi.nlm.nih.gov/19096741/)]
21. Bernardon S, Babb KA, Hakim-Larson J, Gragg M. Loneliness, attachment, and the perception and use of social support in university students. *Can J Behav Sci* 2011;43(1):40-51. [doi: [10.1037/a0021199](https://doi.org/10.1037/a0021199)]
22. Kwan MY, Arbour-Nicitopoulos KP, Duku E, Faulkner G. Patterns of multiple health risk-behaviours in university students and their association with mental health: application of latent class analysis. *Health Promot Chronic Dis Prev Can* 2016 Aug;36(8):163-170 [FREE Full text] [doi: [10.24095/hpcdp.36.8.03](https://doi.org/10.24095/hpcdp.36.8.03)] [Medline: [27556920](https://pubmed.ncbi.nlm.nih.gov/27556920/)]
23. Stults-Kolehmainen MA, Sinha R. The effects of stress on physical activity and exercise. *Sports Med* 2014 Jan;44(1):81-121 [FREE Full text] [doi: [10.1007/s40279-013-0090-5](https://doi.org/10.1007/s40279-013-0090-5)] [Medline: [24030837](https://pubmed.ncbi.nlm.nih.gov/24030837/)]
24. Klaperski S. [Exercise, stress, and health: the stress-buffering effect of exercise]. In: Fuchs R, Gerber M, editors. [Handbook of Stress Regulation and Sport]. Berlin: Springer; 2018:227-249.
25. World health statistics 2019: monitoring health for the SDGs, sustainable development goals. Geneva: World Health Organization; 2019. URL: https://www.who.int/gho/publications/world_health_statistics/2019/EN_WHS_2019_Main.pdf?ua=1 [accessed 2020-10-29]
26. Dogra S, MacIntosh L, O'Neill C, D'Silva C, Shearer H, Smith K, et al. The association of physical activity with depression and stress among post-secondary school students: a systematic review. *Ment Health Phys Act* 2018 Mar;14:146-156. [doi: [10.1016/j.mhpa.2017.11.001](https://doi.org/10.1016/j.mhpa.2017.11.001)]
27. Štefan L, Sporiš G, Krističević T. Are lower levels of physical activity and self-rated fitness associated with higher levels of psychological distress in Croatian young adults? A cross-sectional study. *PeerJ* 2018;6:e4700 [FREE Full text] [doi: [10.7717/peerj.4700](https://doi.org/10.7717/peerj.4700)] [Medline: [29736338](https://pubmed.ncbi.nlm.nih.gov/29736338/)]
28. Felez-Nobrega M, Bort-Roig J, Briones L, Sanchez-Niubo A, Koyanagi A, Puigoriol E, et al. Self-reported and activPAL-monitored physical activity and sedentary behaviour in college students: not all sitting behaviours are linked to perceived stress and anxiety. *J Sports Sci* 2020 Jul;38(13):1566-1574. [doi: [10.1080/02640414.2020.1748359](https://doi.org/10.1080/02640414.2020.1748359)] [Medline: [32279592](https://pubmed.ncbi.nlm.nih.gov/32279592/)]
29. Tyson P, Wilson K, Crone D, Brailsford R, Laws K. Physical activity and mental health in a student population. *J Ment Health* 2010 Dec;19(6):492-499. [doi: [10.3109/09638230902968308](https://doi.org/10.3109/09638230902968308)] [Medline: [20812852](https://pubmed.ncbi.nlm.nih.gov/20812852/)]
30. Joseph RP, Roysse KE, Benitez TJ, Pekmezi DW. Physical activity and quality of life among university students: exploring self-efficacy, self-esteem, and affect as potential mediators. *Qual Life Res* 2014 Mar;23(2):659-667. [doi: [10.1007/s11136-013-0492-8](https://doi.org/10.1007/s11136-013-0492-8)] [Medline: [23928820](https://pubmed.ncbi.nlm.nih.gov/23928820/)]
31. Pengpid S, Peltzer K. Vigorous physical activity, perceived stress, sleep and mental health among university students from 23 low- and middle-income countries. *Int J Adolesc Med Health* 2018 Jan 13;32(2):1-7. [doi: [10.1515/ijamh-2017-0116](https://doi.org/10.1515/ijamh-2017-0116)] [Medline: [29331097](https://pubmed.ncbi.nlm.nih.gov/29331097/)]
32. Panahi S, Tremblay A. Sedentariness and health: is sedentary behavior more than just physical inactivity? *Front Public Health* 2018;6:258 [FREE Full text] [doi: [10.3389/fpubh.2018.00258](https://doi.org/10.3389/fpubh.2018.00258)] [Medline: [30250838](https://pubmed.ncbi.nlm.nih.gov/30250838/)]
33. Vancampfort D, Ashdown-Franks G, Smith L, Firth J, Van Damme T, Christiaansen L, et al. Leisure-time sedentary behavior and loneliness among 148,045 adolescents aged 12-15 years from 52 low- and middle-income countries. *J Affect Disord* 2019 May 15;251:149-155. [doi: [10.1016/j.jad.2019.03.076](https://doi.org/10.1016/j.jad.2019.03.076)] [Medline: [30925265](https://pubmed.ncbi.nlm.nih.gov/30925265/)]
34. Endrighi R, Steptoe A, Hamer M. The effect of experimentally induced sedentariness on mood and psychobiological responses to mental stress. *Br J Psychiatry* 2016 Mar;208(3):245-251 [FREE Full text] [doi: [10.1192/bjp.bp.114.150755](https://doi.org/10.1192/bjp.bp.114.150755)] [Medline: [26294364](https://pubmed.ncbi.nlm.nih.gov/26294364/)]
35. Lee E, Kim Y. Effect of university students' sedentary behavior on stress, anxiety, and depression. *Perspect Psychiatr Care* 2018 May 24;55(2):164-169. [doi: [10.1111/ppc.12296](https://doi.org/10.1111/ppc.12296)]

36. Ge Y, Xin S, Luan D, Zou Z, Bai X, Liu M, et al. Independent and combined associations between screen time and physical activity and perceived stress among college students. *Addict Behav* 2020 Apr;103:106224. [doi: [10.1016/j.addbeh.2019.106224](https://doi.org/10.1016/j.addbeh.2019.106224)] [Medline: [31862620](https://pubmed.ncbi.nlm.nih.gov/31862620/)]
37. Gerber M, Brand S, Herrmann C, Colledge F, Holsboer-Trachsler E, Pühse U. Increased objectively assessed vigorous-intensity exercise is associated with reduced stress, increased mental health and good objective and subjective sleep in young adults. *Physiol Behav* 2014 Aug;135:17-24. [doi: [10.1016/j.physbeh.2014.05.047](https://doi.org/10.1016/j.physbeh.2014.05.047)] [Medline: [24905432](https://pubmed.ncbi.nlm.nih.gov/24905432/)]
38. Lindwall M, Ljung T, Hadžibajramović E, Jonsdottir IH. Self-reported physical activity and aerobic fitness are differently related to mental health. *Ment Health Phys Act* 2012 Jun;5(1):28-34. [doi: [10.1016/j.mhpa.2011.12.003](https://doi.org/10.1016/j.mhpa.2011.12.003)]
39. Jonsdottir IH, Rödger L, Hadžibajramovic E, Börjesson M, Ahlberg G. A prospective study of leisure-time physical activity and mental health in Swedish health care workers and social insurance officers. *Prev Med* 2010 Nov;51(5):373-377. [doi: [10.1016/j.yjmed.2010.07.019](https://doi.org/10.1016/j.yjmed.2010.07.019)] [Medline: [20691721](https://pubmed.ncbi.nlm.nih.gov/20691721/)]
40. Paolucci EM, Loukov D, Bowdish DME, Heisz JJ. Exercise reduces depression and inflammation but intensity matters. *Biol Psychol* 2018 Mar;133:79-84. [doi: [10.1016/j.biopsycho.2018.01.015](https://doi.org/10.1016/j.biopsycho.2018.01.015)] [Medline: [29408464](https://pubmed.ncbi.nlm.nih.gov/29408464/)]
41. Eysenbach G. Improving the quality of web surveys: the checklist for reporting results of internet e-surveys (CHERRIES). *J Med Internet Res* 2004 Sep 29;6(3):e34 [FREE Full text] [doi: [10.2196/jmir.6.3.e34](https://doi.org/10.2196/jmir.6.3.e34)] [Medline: [15471760](https://pubmed.ncbi.nlm.nih.gov/15471760/)]
42. Craig CL, Marshall AL, Sjöström M, Bauman AE, Booth ML, Ainsworth BE, et al. International physical activity questionnaire: 12-country reliability and validity. *Med Sci Sports Exerc* 2003 Aug;35(8):1381-1395. [doi: [10.1249/01.MSS.0000078924.61453.FB](https://doi.org/10.1249/01.MSS.0000078924.61453.FB)] [Medline: [12900694](https://pubmed.ncbi.nlm.nih.gov/12900694/)]
43. Rodríguez-Muñoz S, Corella C, Abarca-Sos A, Zaragoza J. Validation of three short physical activity questionnaires with accelerometers among university students in Spain. *J Sports Med Phys Fitness* 2017 Dec;57(12):1660-1668. [doi: [10.23736/S0022-4707.17.06665-8](https://doi.org/10.23736/S0022-4707.17.06665-8)] [Medline: [28249383](https://pubmed.ncbi.nlm.nih.gov/28249383/)]
44. Cohen S, Kamarck T, Mermelstein R. A global measure of perceived stress. *J Health Soc Behav* 1983 Dec;24(4):385-396. [Medline: [6668417](https://pubmed.ncbi.nlm.nih.gov/6668417/)]
45. Klein EM, Brähler E, Dreier M, Reinecke L, Müller KW, Schmutz G, et al. The German version of the Perceived Stress Scale: psychometric characteristics in a representative German community sample. *BMC Psychiatry* 2016 Dec 23;16:159 [FREE Full text] [doi: [10.1186/s12888-016-0875-9](https://doi.org/10.1186/s12888-016-0875-9)] [Medline: [27216151](https://pubmed.ncbi.nlm.nih.gov/27216151/)]
46. Ganz T, Braun M, Laging M, Heidenreich T. Erfassung des riskanten Alkoholkonsums bei Studierenden deutscher Hochschulen. *Z Klin Psychol Psychother* 2017 Jul;46(3):187-197. [doi: [10.1026/1616-3443/a000432](https://doi.org/10.1026/1616-3443/a000432)]
47. Famodu OA, Barr ML, Holásková I, Zhou W, Morrell JS, Colby SE, et al. Shortening of the Pittsburgh Sleep Quality Index Survey using factor analysis. *Sleep Disord* 2018;2018:9643937 [FREE Full text] [doi: [10.1155/2018/9643937](https://doi.org/10.1155/2018/9643937)] [Medline: [29850262](https://pubmed.ncbi.nlm.nih.gov/29850262/)]
48. Guidelines for data processing and analysis of the International Physical Activity Questionnaire. URL: <http://www.ipaq.ki.se/scoring.pdf> [accessed 2020-10-29]
49. Ekelund U, Brown WJ, Steene-Johannessen J, Fagerland MW, Owen N, Powell KE, et al. Do the associations of sedentary behaviour with cardiovascular disease mortality and cancer mortality differ by physical activity level? A systematic review and harmonised meta-analysis of data from 850 060 participants. *Br J Sports Med* 2019 Jul;53(14):886-894. [doi: [10.1136/bjsports-2017-098963](https://doi.org/10.1136/bjsports-2017-098963)] [Medline: [29991570](https://pubmed.ncbi.nlm.nih.gov/29991570/)]
50. Ekelund U, Steene-Johannessen J, Brown WJ, Fagerland MW, Owen N, Powell KE, et al. Does physical activity attenuate, or even eliminate, the detrimental association of sitting time with mortality? A harmonised meta-analysis of data from more than 1 million men and women. *Lancet* 2016 Sep;388(10051):1302-1310. [doi: [10.1016/s0140-6736\(16\)30370-1](https://doi.org/10.1016/s0140-6736(16)30370-1)]
51. Stamatakis E, Gale J, Bauman A, Ekelund U, Hamer M, Ding D. Sitting time, physical activity, and risk of mortality in adults. *J Am Coll Cardiol* 2019 Apr 30;73(16):2062-2072 [FREE Full text] [doi: [10.1016/j.jacc.2019.02.031](https://doi.org/10.1016/j.jacc.2019.02.031)] [Medline: [31023430](https://pubmed.ncbi.nlm.nih.gov/31023430/)]
52. Vankim NA, Nelson TF. Vigorous physical activity, mental health, perceived stress, and socializing among college students. *Am J Health Promot* 2013;28(1):7-15 [FREE Full text] [doi: [10.4278/ajhp.111101-QUAN-395](https://doi.org/10.4278/ajhp.111101-QUAN-395)] [Medline: [23470187](https://pubmed.ncbi.nlm.nih.gov/23470187/)]
53. Lovell GP, Nash K, Sharman R, Lane BR. A cross-sectional investigation of depressive, anxiety, and stress symptoms and health-behavior participation in Australian university students. *Nurs Health Sci* 2015 Mar;17(1):134-142. [doi: [10.1111/nhs.12147](https://doi.org/10.1111/nhs.12147)] [Medline: [24799077](https://pubmed.ncbi.nlm.nih.gov/24799077/)]
54. Mikkelsen K, Stojanovska L, Polenakovic M, Bosevski M, Apostolopoulos V. Exercise and mental health. *Maturitas* 2017 Dec;106:48-56. [doi: [10.1016/j.maturitas.2017.09.003](https://doi.org/10.1016/j.maturitas.2017.09.003)] [Medline: [29150166](https://pubmed.ncbi.nlm.nih.gov/29150166/)]
55. Ekelund U, Tarp J, Steene-Johannessen J, Hansen BH, Jefferis B, Fagerland MW, et al. Dose-response associations between accelerometry measured physical activity and sedentary time and all cause mortality: systematic review and harmonised meta-analysis. *BMJ* 2019 Aug 21;366:i4570. [doi: [10.1136/bmj.l4570](https://doi.org/10.1136/bmj.l4570)] [Medline: [31434697](https://pubmed.ncbi.nlm.nih.gov/31434697/)]
56. Teychenne M, White RL, Richards J, Schuch FB, Rosenbaum S, Bennie JA. Do we need physical activity guidelines for mental health: what does the evidence tell us? *Ment Health Phys Act* 2020 Mar;18:100315. [doi: [10.1016/j.mhpa.2019.100315](https://doi.org/10.1016/j.mhpa.2019.100315)]
57. Hallgren M, Dunstan DW, Owen N. Passive versus mentally active sedentary behaviors and depression. *Exerc Sport Sci Rev* 2020 Jan;48(1):20-27. [doi: [10.1249/JES.0000000000000211](https://doi.org/10.1249/JES.0000000000000211)] [Medline: [31663866](https://pubmed.ncbi.nlm.nih.gov/31663866/)]

58. Zhai X, Ye M, Wang C, Gu Q, Huang T, Wang K, et al. Associations among physical activity and smartphone use with perceived stress and sleep quality of Chinese college students. *Ment Health Phys Act* 2020 Mar;18:100323. [doi: [10.1016/j.mhpa.2020.100323](https://doi.org/10.1016/j.mhpa.2020.100323)]
59. Teychenne M, Costigan SA, Parker K. The association between sedentary behaviour and risk of anxiety: a systematic review. *BMC Public Health* 2015 Jun 19;15:513 [FREE Full text] [doi: [10.1186/s12889-015-1843-x](https://doi.org/10.1186/s12889-015-1843-x)] [Medline: [26088005](https://pubmed.ncbi.nlm.nih.gov/26088005/)]
60. Zhai L, Zhang Y, Zhang D. Sedentary behaviour and the risk of depression: a meta-analysis. *Br J Sports Med* 2015 Jun;49(11):705-709. [doi: [10.1136/bjsports-2014-093613](https://doi.org/10.1136/bjsports-2014-093613)] [Medline: [25183627](https://pubmed.ncbi.nlm.nih.gov/25183627/)]
61. Gerber M, Ludyga S, Mücke M, Colledge F, Brand S, Pühse U. Low vigorous physical activity is associated with increased adrenocortical reactivity to psychosocial stress in students with high stress perceptions. *Psychoneuroendocrinology* 2017 Jun;80:104-113. [doi: [10.1016/j.psyneuen.2017.03.004](https://doi.org/10.1016/j.psyneuen.2017.03.004)] [Medline: [28324699](https://pubmed.ncbi.nlm.nih.gov/28324699/)]
62. Sallis JF, Saelens BE. Assessment of physical activity by self-report: status, limitations, and future directions. *Res Q Exerc Sport* 2000 Jun;71(2 Suppl):S1-S14. [Medline: [10925819](https://pubmed.ncbi.nlm.nih.gov/10925819/)]
63. Di Benedetto M, Towt CJ, Jackson ML. A cluster analysis of sleep quality, self-care behaviors, and mental health risk in Australian university students. *Behav Sleep Med* 2020;18(3):309-320. [doi: [10.1080/15402002.2019.1580194](https://doi.org/10.1080/15402002.2019.1580194)] [Medline: [30821507](https://pubmed.ncbi.nlm.nih.gov/30821507/)]
64. Murphy MH, Carlin A, Woods C, Nevill A, MacDonncha C, Ferguson K, et al. Active students are healthier and happier than their inactive peers: the results of a large representative cross-sectional study of University students in Ireland. *J Phys Act Health* 2018 Oct 01;15(10):737-746. [doi: [10.1123/jpah.2017-0432](https://doi.org/10.1123/jpah.2017-0432)] [Medline: [30119614](https://pubmed.ncbi.nlm.nih.gov/30119614/)]
65. Seo EJ, Ahn J, Hayman LL, Kim C. The association between perceived stress and quality of life in university students: the parallel mediating role of depressive symptoms and health-promoting behaviors. *Asian Nurs Res (Korean Soc Nurs Sci)* 2018 Sep;12(3):190-196 [FREE Full text] [doi: [10.1016/j.anr.2018.08.001](https://doi.org/10.1016/j.anr.2018.08.001)] [Medline: [30103040](https://pubmed.ncbi.nlm.nih.gov/30103040/)]
66. Chan HWQ, Sun CFR. Irrational beliefs, depression, anxiety, and stress among university students in Hong Kong. *J Am Coll Health* 2020 Mar 09;1-15. [doi: [10.1080/07448481.2019.1710516](https://doi.org/10.1080/07448481.2019.1710516)] [Medline: [32149578](https://pubmed.ncbi.nlm.nih.gov/32149578/)]
67. Gerber M, Schilling R, Colledge F, Ludyga S, Pühse U, Brand S. More than a simple pastime? The potential of physical activity to moderate the relationship between occupational stress and burnout symptoms. *Int J Stress Manag* 2020 Feb;27(1):53-64. [doi: [10.1037/str0000129](https://doi.org/10.1037/str0000129)]
68. Ge Y, Xin S, Luan D, Zou Z, Liu M, Bai X, et al. Association of physical activity, sedentary time, and sleep duration on the health-related quality of life of college students in Northeast China. *Health Qual Life Outcomes* 2019 Jul 16;17(1):124 [FREE Full text] [doi: [10.1186/s12955-019-1194-x](https://doi.org/10.1186/s12955-019-1194-x)] [Medline: [31311564](https://pubmed.ncbi.nlm.nih.gov/31311564/)]

Abbreviations

AUDIT-C: Alcohol Use Disorders Identification Test for Consumption

CHERRIES: Checklist for Reporting Results of Internet E-Surveys

IPAQ-SF: International Physical Activity Questionnaire Short Form

MET: metabolic equivalent of task

mPA: moderate physical activity

PA: physical activity

PSS: Perceived Stress Scale

sPSQI: short-form Pittsburgh Sleep Quality Index

ST: sedentary time

vPA: vigorous physical activity

Edited by G Eysenbach; submitted 11.05.20; peer-reviewed by M Ellingsen, B Bock; comments to author 19.08.20; revised version received 06.10.20; accepted 24.10.20; published 11.11.20.

Please cite as:

Tan SL, Jetzke M, Vergeld V, Müller C

Independent and Combined Associations of Physical Activity, Sedentary Time, and Activity Intensities With Perceived Stress Among University Students: Internet-Based Cross-Sectional Study

JMIR Public Health Surveill 2020;6(4):e20119

URL: <http://publichealth.jmir.org/2020/4/e20119/>

doi: [10.2196/20119](https://doi.org/10.2196/20119)

PMID: [33174855](https://pubmed.ncbi.nlm.nih.gov/33174855/)

©Shu Ling Tan, Malte Jetzke, Vera Vergeld, Carsten Müller. Originally published in *JMIR Public Health and Surveillance* (<http://publichealth.jmir.org>), 11.11.2020. This is an open-access article distributed under the terms of the Creative Commons

Attribution License (<https://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in JMIR Public Health and Surveillance, is properly cited. The complete bibliographic information, a link to the original publication on <http://publichealth.jmir.org>, as well as this copyright and license information must be included.

Corrigenda and Addenda

Correction Diagnostic Accuracy of Chest Computed Tomography Scans for Suspected Patients With COVID-19: Receiver Operating Characteristic Curve Analysis

Lianpin Wu¹, MD; Qike Jin¹, MD; Jie Chen², MD, PhD; Jiawei He¹, MD; David M Brett-Major³, MD; Jianghu James Dong⁴, PhD

¹Department of Cardiology, the Second Affiliated Hospital & Yuying Children's Hospital of Wenzhou Medical University, Wenzhou, China

²College of Optometry, Wenzhou Medical University, Wenzhou, China

³Department of Epidemiology, University of Nebraska Medical Center, Omaha, NE, United States

⁴Department of Biostatistics and Department of Medicine, University of Nebraska Medical Center, Omaha, NE, United States

Corresponding Author:

Jianghu James Dong, PhD

Department of Biostatistics and Department of Medicine

University of Nebraska Medical Center

984375 Nebraska Medical Center

Omaha, NE, 68198-4375

United States

Phone: 1 402 559 1976

Email: jianghu.dong@unmc.edu

Related Article:

Correction of: <https://publichealth.jmir.org/2020/4/e19424/>

(*JMIR Public Health Surveill* 2020;6(4):e25829) doi:[10.2196/25829](https://doi.org/10.2196/25829)

In "Diagnostic Accuracy of Chest Computed Tomography Scans for Suspected Patients With COVID-19: Receiver Operating Characteristic Curve Analysis" (*JMIR Public Health Surveill* 2020;6(4):e19424), the authors noted one error.

The affiliation for authors Lianpin Wu, Qike Jin, and Jiawei He was incorrectly listed as:

Department of Cardiology, Wenzhou Medical University, Wenzhou, China

The affiliation for these authors has been corrected to:

Department of Cardiology, the Second Affiliated Hospital & Yuying Children's Hospital of Wenzhou Medical University, Wenzhou, China

The correction will appear in the online version of the paper on the JMIR Publications website on November 20, 2020, together with the publication of this correction notice. Because this was made after submission to PubMed, PubMed Central, and other full-text repositories, the corrected article has also been resubmitted to those repositories.

Submitted 17.11.20; this is a non-peer-reviewed article; accepted 17.11.20; published 20.11.20.

Please cite as:

Wu L, Jin Q, Chen J, He J, Brett-Major DM, Dong JJ

Correction: Diagnostic Accuracy of Chest Computed Tomography Scans for Suspected Patients With COVID-19: Receiver Operating Characteristic Curve Analysis

JMIR Public Health Surveill 2020;6(4):e25829

URL: <http://publichealth.jmir.org/2020/4/e25829/>

doi:[10.2196/25829](https://doi.org/10.2196/25829)

PMID:[33216725](https://pubmed.ncbi.nlm.nih.gov/33216725/)

©Lianpin Wu, Qike Jin, Jie Chen, Jiawei He, David M Brett-Major, Jianghu James Dong. Originally published in JMIR Public Health and Surveillance (<http://publichealth.jmir.org>), 20.11.2020. This is an open-access article distributed under the terms of the Creative Commons Attribution License (<https://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in JMIR Public Health and Surveillance, is properly cited. The complete bibliographic information, a link to the original publication on <http://publichealth.jmir.org>, as well as this copyright and license information must be included.

Letter to the Editor

Importance of Educating Teenagers on Appropriate Safety Gear for E-Scooters. Comment on “Follow-Up Investigation on the Promotional Practices of Electric Scooter Companies: Content Analysis of Posts on Instagram and Twitter”

Claire SooHoo¹; Jackson SooHoo¹

Geffen Academy at UCLA, Los Angeles, CA, United States

Corresponding Author:

Claire SooHoo

Geffen Academy at UCLA

11270 Exposition Blvd

PO Box 64171

Los Angeles, CA, 90064

United States

Phone: 1 310 869 6936

Email: csoohoo99@geffenacademy.ucla.edu

Related Article:

Comment on: <https://publichealth.jmir.org/2020/1/e16833/>

(*JMIR Public Health Surveill* 2020;6(4):e18945) doi:[10.2196/18945](https://doi.org/10.2196/18945)

KEYWORDS

e-scooters; trauma; electric scooter; public safety; road safety; public health; safety equipment; teenagers

My brother and I are writing a letter in response to the paper “Follow-Up Investigation on the Promotional Practices of Electric Scooter Companies: Content Analysis of Posts on Instagram and Twitter” by Dormanesh et al [1].

The paper discusses the promotion of proper safety equipment for riding electric scooters (e-scooters) online. The authors found that the social media accounts of prominent e-scooter companies Bird and Tier Mobility rarely, if ever, included photos of people wearing equipment such as helmets, knee pads, or wrist guards. To expand on this subject, Dormanesh and colleagues [1] could consider how e-scooter companies’ practices should better communicate or call attention to safety guidelines. We are both teenagers in high school and the dangers of e-scooters are familiar to us. The use of e-scooters, especially provided by rideshare companies such as Bird or Lime, has grown increasingly common among our peers in recent years. Especially in dense metropolitan areas, e-scooters can be extremely convenient for quick transportation. However, this ease of access also presents a problem of safety. We have noticed that in using these e-scooters, many of our fellow teenagers often fail to follow proper safety conventions. We almost never see anyone riding on a scooter with a helmet or other safety gear. Furthermore, there is no designated pathway

for motorized scooters, and thus it can become hazardous for pedestrians on the sidewalk or on the road.

The importance of educating teenagers on appropriate safety gear is supported by recent research done reporting e-scooter injuries in the pediatric population. A previous study of 990 patients who sustained craniofacial injuries due to motorized scooter use shows that almost 50% of the injuries were to children under the age of 18 years, including 33% who were under the age of 12 [2]. A study conducted in Copenhagen revealed that over 10% of the patients studied who received injuries from using e-scooters were under the age of 18 [3]. Lastly, a study conducted locally at the University of California, Los Angeles, showed that 4 out of the 73 patients studied who sustained operative orthopedic injuries as a result of e-scooter use were adolescents [4]. All of these studies suggest that children and adolescents around the world are ignoring safety restrictions and riding e-scooters despite being underage. Although there are some restrictions for using the service such as owning a driver’s license and being at least 18 years old, these rules are easy to bypass. For example, many of our friends use their parents’ licenses to ride scooters. Stricter enforcement and more awareness of these regulations are necessary to decrease the risk of injury.

E-scooter accidents are currently difficult to accurately track in injury databases. A recent paper examined e-scooters using the “hoverboard” category from the National Electronic Injury Surveillance System, which includes electrically powered skateboards [5]. The lack of more specific coding results in unreliable data on the incidence of e-scooter injuries. We have also noted a similar issue with ICD-10-CM (International Classification of Diseases, Tenth Revision, Clinical Modification) coding. We attempted to examine the incidence of scooter injuries using the Patient Discharge Database in California. As a result of the absence of coding for e-scooter

accidents, we used a proxy code, V03.19, which identifies pedestrians on conveyances other than roller skates or skateboards [6]. The demographics of this code are more consistent with e-scooter injuries than the code for motorized mobility scooters (V00.83), which included an older and less ethnically diverse group of patients (Table 1). Despite this, the lack of a more specific code limits our ability to accurately track e-scooter injuries. The implementation of proper coding for documentation in medical records would be valuable to researchers, hospitals, and the public in understanding the true risks and public health impact of e-scooter injuries.

Table 1. Demographics for the electronic scooter rider proxy code V03.19 compared to motorized mobility scooter riders (V00.83).

Patient characteristic	Electronic scooter proxy (n=402)	Motorized mobility scooters (n=165)	P value
Age (years), mean	51	68	<.001
Race/ethnicity (% White)	53	82	<.001
Insurance type (% uninsured)	6	2	<.001
Sex (% male)	69	85	<.001

Editorial Notice

The first author of the cited manuscript [1] Allison Dormanesh reviewed this Letter to the Editor but chose not to reply.

Conflicts of Interest

None declared.

References

1. Dormanesh A, Majmundar A, Allem JP. Follow-Up Investigation on the Promotional Practices of Electric Scooter Companies: Content Analysis of Posts on Instagram and Twitter. *JMIR Public Health Surveill* 2020 Jan 23;6(1):e16833 [FREE Full text] [doi: [10.2196/16833](https://doi.org/10.2196/16833)] [Medline: [32012087](https://pubmed.ncbi.nlm.nih.gov/32012087/)]
2. Namiri NK, Lui H, Tangney T, Allen IE, Cohen AJ, Breyer BN. Electric Scooter Injuries and Hospital Admissions in the United States, 2014-2018. *JAMA Surg* 2020 Apr 01;155(4):357-359. [doi: [10.1001/jamasurg.2019.5423](https://doi.org/10.1001/jamasurg.2019.5423)] [Medline: [31913417](https://pubmed.ncbi.nlm.nih.gov/31913417/)]
3. Bandzar S, Funsch DG, Hermansen R, Gupta S, Bandzar A. Pediatric Hoverboard and Skateboard Injuries. *Pediatrics* 2018 Apr;141(4). [doi: [10.1542/peds.2017-1253](https://doi.org/10.1542/peds.2017-1253)] [Medline: [29581182](https://pubmed.ncbi.nlm.nih.gov/29581182/)]
4. Ishmael CR, Hsiue PP, Zoller SD, Wang P, Hori KR, Gatto JD, et al. An Early Look at Operative Orthopaedic Injuries Associated with Electric Scooter Accidents: Bringing High-Energy Trauma to a Wider Audience. *J Bone Joint Surg Am* 2020 Mar 04;102(5):e18. [doi: [10.2106/JBJS.19.00390](https://doi.org/10.2106/JBJS.19.00390)] [Medline: [31895168](https://pubmed.ncbi.nlm.nih.gov/31895168/)]
5. National Electronic Injury Surveillance System (NEISS) Coding Manual. U.S. Consumer Product Safety Commission. 2019. URL: https://www.cpsc.gov/s3fs-public/2019_NEISS_Coding_Manual.pdf [accessed 2020-03-25]
6. SooHoo JF, SooHoo CF, Cash B, Johnson EE, SooHoo NF. The cost and severity of orthopaedic injuries suffered in motorized scooter accidents in California. Poster Presentation. 2020 Presented at: American Academy of Orthopaedic Surgeons Annual Meeting; March 24-28; Orlando, FL.

Abbreviations

e-scooter: electric scooter

ICD-10-CM: International Classification of Diseases, Tenth Revision, Clinical Modification

Edited by G Eysenbach, T Derrick; submitted 28.03.20; peer-reviewed by JP Allem; comments to author 10.08.20; revised version received 23.08.20; accepted 01.10.20; published 27.10.20.

Please cite as:

SooHoo C, SooHoo J

Importance of Educating Teenagers on Appropriate Safety Gear for E-Scooters. Comment on “Follow-Up Investigation on the Promotional Practices of Electric Scooter Companies: Content Analysis of Posts on Instagram and Twitter”

JMIR Public Health Surveill 2020;6(4):e18945

URL: <http://publichealth.jmir.org/2020/4/e18945/>

doi: [10.2196/18945](https://doi.org/10.2196/18945)

PMID: [33107834](https://pubmed.ncbi.nlm.nih.gov/33107834/)

©Claire SooHoo, Jackson SooHoo. Originally published in JMIR Public Health and Surveillance (<http://publichealth.jmir.org>), 27.10.2020. This is an open-access article distributed under the terms of the Creative Commons Attribution License (<https://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in JMIR Public Health and Surveillance, is properly cited. The complete bibliographic information, a link to the original publication on <http://publichealth.jmir.org>, as well as this copyright and license information must be included.

Letter to the Editor

Errors in Tracing Coronavirus SARS-CoV-2 Transmission Using a Maximum Likelihood Tree. Comment on “A Snapshot of SARS-CoV-2 Genome Availability up to April 2020 and its Implications: Data Analysis”

Peter Forster¹, PhD; Lucy Forster², PhD

¹McDonald Institute, University of Cambridge, Cambridge, United Kingdom

²Lakeside Healthcare Group at Cedar House Surgery – NHS, St Neots, United Kingdom

Corresponding Author:

Peter Forster, PhD
McDonald Institute
University of Cambridge
Downing Site
Cambridge, CB2 3ER
United Kingdom
Email: pf223@cam.ac.uk

Related Articles:

Comment on: <https://publichealth.jmir.org/2020/2/e19170/>

Comment in: <https://publichealth.jmir.org/2020/4/e24661/>

(*JMIR Public Health Surveill* 2020;6(4):e23542) doi:[10.2196/23542](https://doi.org/10.2196/23542)

KEYWORDS

coronavirus; SARS-CoV-2; genome; phylogenetic; network; tracing; tracking; transmission; dissemination; infection; geography; route

Tracing and quarantining symptomatic and asymptomatic individuals infected by the novel coronavirus SARS-CoV-2 is an important approach to controlling the current epidemic. Tracing the source of an infection can be achieved by conventional interviews, by mobile telephone tracking, or by phylogenetic tracing of the virus genomes themselves, as we have proposed in our work [1].

In a recent critique in *JMIR Public Health and Surveillance* [2] (also see our reply [3]), Mavian and colleagues have disputed our phylogenetic tracing approach and concluded: “it is not possible with the present data to decide which branching pattern (and, therefore, which phylogeographic reconstruction) most likely represents actual dissemination routes among European countries.”

Their underlying reanalysis is, however, based on a trivial oversight. They analyzed genomes collected worldwide in early March 2020 and initially confirmed the B-subclade that we had identified, which links a German sequence to an Italian sequence and thence to further Finnish, Mexican, Swiss, and German sequences. However, they then claim, “in a new tree inferred

just one week later, when more than 135 new full genome sequences were made available on GISAID, the direct link between Germany and Italy [...] disappeared due to additional clustering of [five] previously unsampled sequences from Portugal, Brazil, Wales, and [two from] the Netherlands.”

Upon request, Dr Mavian provided us with a file of these five new sequences. Comparing these five in our coronavirus sequence alignment table (freely available on the Fluxus Technology website [4]), it transpires that these five sequences are identical to each other and to the pre-existing Italian sequence. Mavian and colleagues [2] appear not to have noticed the identity as they fail to mention it; instead, they present a “maximum likelihood” tree, which misleadingly shows these five new sequences and the pre-existing Italian sequence to be separated by apparently deep branches, even though they are identical. Mavian and colleagues [2] appear to have relied on their computer program without investigating their entered sequences.

Moreover, Mavian and colleagues [2] have not presented the documented patient travel histories of the five new viral

sequences. We present these now, using freely available GISAID (Global Initiative on Sharing All Influenza Data) information [5] and contemporary reports, and find that all patients (ie, the Welshman [6,7], both Dutch [8,9], and the Brazilian [GISAID access 412964]) had visited Italy a few days before falling ill. The Portuguese (GISAID access 413648) had visited Spain.

Thus, in four of the five new cases, the patient's travel history to Italy confirms the viral sequence match to the pre-existing Italian sequence. It is therefore unfounded for Mavian and colleagues [2] to claim that the data cannot reveal branching patterns or likely dissemination routes among European countries.

Conflicts of Interest

None declared.

References

1. Forster P, Forster L, Renfrew C, Forster M. Phylogenetic network analysis of SARS-CoV-2 genomes. *Proc Natl Acad Sci U S A* 2020 Apr 28;117(17):9241-9243 [FREE Full text] [doi: [10.1073/pnas.2004999117](https://doi.org/10.1073/pnas.2004999117)] [Medline: [32269081](https://pubmed.ncbi.nlm.nih.gov/32269081/)]
2. Mavian C, Marini S, Prosperi M, Salemi M. A Snapshot of SARS-CoV-2 Genome Availability up to April 2020 and its Implications: Data Analysis. *JMIR Public Health Surveill* 2020 Jun 1;6(2):e19170. [doi: [10.2196/19170](https://doi.org/10.2196/19170)] [Medline: [32412415](https://pubmed.ncbi.nlm.nih.gov/32412415/)]
3. Forster P, Forster L, Renfrew C, Forster M. Reply to Sánchez-Pacheco et al., Chookajorn, and Mavian et al.: Explaining phylogenetic network analysis of SARS-CoV-2 genomes. *Proc Natl Acad Sci U S A* 2020 Jun 09;117(23):12524-12525. [doi: [10.1073/pnas.2007433117](https://doi.org/10.1073/pnas.2007433117)] [Medline: [32439706](https://pubmed.ncbi.nlm.nih.gov/32439706/)]
4. Fluxus Technology. URL: <https://www.fluxus-technology.com/> [accessed 2020-10-13]
5. GISAID. 2020. URL: <https://www.gisaid.org/> [accessed 2020-10-13]
6. Coronavirus: Wales' first patient urges positivity. *BBC News*. 2020 May 6. URL: <https://www.bbc.com/news/uk-wales-52561210> [accessed 2020-10-13]
7. Cooper J. Meet Wales' first COVID patient. *Western Mail*. 2020 Jun 8. URL: <https://www.pressreader.com/uk/western-mail/20200608/282076279099626> [accessed 2020-10-13]
8. Stoop S. Twee mensen in 't Gooi besmet met het coronavirus (Two people in Gooi infected with coronavirus). *NHNieuws*. 2020 Mar 4. URL: <https://www.nhnieuws.nl/nieuws/263083/twee-mensen-in-t-gooi-besmet-met-het-coronavirus> [accessed 2020-10-13]
9. de Wijk S. Coronabesmetting in Zeewolde leidt tot reacties (Corona infection in Zeewolde leads to reactions). *Zeewolde-Actueel*. 2020 Mar 5. URL: <https://www.zeewolde-actueel.nl/nieuws/algemeen/207051/coronabesmetting-in-zeewolde-leidt-tot-reacties> [accessed 2020-10-13]

Abbreviations

GISAID: Global Initiative on Sharing All Influenza Data

Edited by T Sanchez, T Derrick; submitted 15.08.20; peer-reviewed by C Mavian; comments to author 18.09.20; revised version received 19.09.20; accepted 23.09.20; published 11.11.20.

Please cite as:

Forster P, Forster L

Errors in Tracing Coronavirus SARS-CoV-2 Transmission Using a Maximum Likelihood Tree. Comment on "A Snapshot of SARS-CoV-2 Genome Availability up to April 2020 and its Implications: Data Analysis"

JMIR Public Health Surveill 2020;6(4):e23542

URL: <http://publichealth.jmir.org/2020/4/e23542/>

doi:[10.2196/23542](https://doi.org/10.2196/23542)

PMID:[33174859](https://pubmed.ncbi.nlm.nih.gov/33174859/)

©Peter Forster, Lucy Forster. Originally published in *JMIR Public Health and Surveillance* (<http://publichealth.jmir.org>), 11.11.2020. This is an open-access article distributed under the terms of the Creative Commons Attribution License (<https://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in *JMIR Public Health and Surveillance*, is properly cited. The complete bibliographic information, a link to the original publication on <http://publichealth.jmir.org>, as well as this copyright and license information must be included.

Letter to the Editor

Authors' Reply to: Errors in Tracing Coronavirus SARS-CoV-2 Transmission Using a Maximum Likelihood Tree. Comment on “A Snapshot of SARS-CoV-2 Genome Availability up to April 2020 and its Implications: Data Analysis”

Carla Mavian¹, PhD; Simone Marini², PhD; Mattia Prosperi², PhD; Marco Salemi¹, PhD

¹Department of Pathology, Immunology, and Laboratory Medicine, College of Medicine, Emerging Pathogens Institute, University of Florida, Gainesville, FL, United States

²Department of Epidemiology, College of Public Health and Health Professions, Emerging Pathogens Institute, University of Florida, Gainesville, FL, United States

Corresponding Author:

Marco Salemi, PhD

Department of Pathology, Immunology, and Laboratory Medicine, College of Medicine

Emerging Pathogens Institute

University of Florida

2055 Mowry Road

Gainesville, FL, 32610

United States

Phone: 1 3522739419

Email: salemi@pathology.ufl.edu

Related Articles:

Comment on: <https://publichealth.jmir.org/2020/2/e23542/>

Comment on: <https://publichealth.jmir.org/2020/2/e19170/>

(*JMIR Public Health Surveill* 2020;6(4):e24661) doi:[10.2196/24661](https://doi.org/10.2196/24661)

KEYWORDS

SARS-COV-2; phylogeny; cladogram

Before discussing, in detail, the serious technical issues, and conceptual and theoretical mistakes, in the commentary by Forster and Forster [1], we would like to emphasize the following points. First, very recent work by Morel and colleagues [2] has confirmed and further extended our original observation of a lack of a phylogenetic signal in SARS-CoV-2 sequences from the early phase of the pandemic, which is in line with our main criticism that Forster et al's work [3] was based on a superficial analysis of biased and noisy sequence data, resulting at best in misleading conclusions. Second, many of the claims in the paper by Forster et al [3] have been criticized by three independent Letters to the Editor published in the *Proceedings of the National Academy of Sciences* [4-6], including a letter of our own [6], which was signed by over 30 world-renowned experts in phylogenetic analysis, who actually pioneered and contributed to the development of modern phylodynamics. Third, our paper, published in *JMIR Public Health and Surveillance* [7], has also been supported and confirmed by similar findings of other independent investigators [2,8,9], clearly showing that phylogeny-based analyses of

SARS-CoV-2 genomic data, available during the early phase of the pandemic, have led to premature conclusions and/or statistically questionable findings, due to a lack of a phylogenetic signal determined by the sudden emergence and exponential growth of the virus, as well as a strong sampling bias. Indeed, our paper [7] shows that even when new (and more recently sampled) sequences are added to the tree, phylogeographic hypotheses of early SARS-CoV-2 spread in Europe, such as the possible introduction of the virus from Germany to Italy, cannot be proven with sufficient statistical robustness, since the sequence data support several other equally likely scenarios.

It is true that methods such as contact tracing and mobile phone tracking can be very effective in tracking outbreaks [10]. Yet, epidemiological tracing and surveillance by other means was not the focus of our work [7], which discusses only the unreliability of using SARS-CoV-2 sequence data, without the aid of other contact tracing methods, to infer virus dissemination during the early phase of the pandemic. Therefore, one of the

major points raised by Forster and Forster [1] in their commentary is irrelevant since it is not pertinent to our work or the interpretation of our findings.

Forster and Forster [1] misinterpret the message of our paper, based on targeted sentences/paragraphs taken out of context. There was no trivial or other oversight in our analysis. If anything, the subsequent isolation of sequences of patients from Portugal, Brazil, Wales, and the Netherlands, which were identical to the pre-existing Italian sequence, illustrates our point precisely: “it is not possible with the present data to decide which branching pattern (and, therefore, which phylogeographic reconstruction) most likely represents actual dissemination routes among European countries.” Forster and Forster [1] go on to discuss how the Welsh, both Dutch, and Brazilian patients had all visited Italy a few days before falling ill. This is interesting information that may suggest such patients were infected in Italy; after all, contact tracing is presently considered the golden standard for tracking SARS-CoV-2 dissemination, but it has very little to do with the central problem raised in our paper [7]: branching patterns in the phylogeny alone, especially when based on several identical sequences from different geographic areas (one of the very definitions of a lack of a phylogenetic signal in any basic textbook [11], which Forster and Forster [1] seem to ignore) cannot distinguish among different and equally likely dissemination scenarios. In fact, Table 1 in our manuscript shows, as expected given the presence of several identical sequences sampled over a short time interval in different countries, that alternative topologies underlying alternative dissemination scenarios are equally likely. Besides, the SARS-CoV-2 incubation period and the lack of symptoms during early infection should caution against firm conclusions on the directionality of infection even when further details on travel history are available.

Forster and Forster’s [1] critique of Figure 2 exemplifies the extent of their misreading of our paper [7]. As clearly stated in the legend, the maximum likelihood tree in Figure 2 is displayed as a “cladogram,” which means that branch lengths are not drawn proportional to genetic distance or time-scaled. Cladograms are branching diagrams only showing cladistic relationship among taxa, where branches have an arbitrary length chosen for best display purposes [11]. It seems Forster and Forster [1] misread the figure legend, as the confusion between cladogram and phylogram implied in their rebuttal would be quite egregious for any scientist with a basic background in phylogenetic analysis; hence, they have not discovered any flaw. The fact that previously unsampled sequences from Portugal, Brazil, Wales, and the Netherlands are identical to the Italian sequence is *exactly* the point we are making: such sequences altogether have no phylogenetic signal (defined as the minimum amount of genetic diversity required to generate resolved phylogenies [11]). In a phylogeny with branch lengths drawn proportional to genetic distances, such sequences would appear to cluster tightly along very short branches of actual zero length, simultaneously arising from a common ancestor. This is what we call in the paper a star-like signal, which is obviously associated with phylogenetic noise, that is, the inability to discern the exact evolutionary relationship among sequences (other than to trivially say that they are all identical and, thus, related through a most recent common ancestor).

In summary, while it is true that identical sequences are likely linked by close transmissions, it is also important to remember that, in the absence of phylogenetic information, it would be impossible to establish the correct sequence of events through phylogeny reconstruction alone, which is the whole point of our paper [7].

Conflicts of Interest

None declared.

References

1. Forster P, Forster L. Errors in Tracing Coronavirus SARS-CoV-2 Transmission Using a Maximum Likelihood Tree. Comment on “A Snapshot of SARS-CoV-2 Genome Availability up to April 2020 and its Implications: Data Analysis”. JMIR Public Health and Surveillance 2020:e23542. [doi: [10.2196/23542](https://doi.org/10.2196/23542)]
2. Morel B, Barbera P, Czech L, Bettisworth B, Hübner L, Lutteropp S, et al. Phylogenetic analysis of SARS-CoV-2 data is difficult.. bioRxiv Preprint posted on August 06, 2020. [FREE Full text] [doi: [10.1101/2020.08.05.239046](https://doi.org/10.1101/2020.08.05.239046)]
3. Forster P, Forster L, Renfrew C, Forster M. Phylogenetic network analysis of SARS-CoV-2 genomes. Proc Natl Acad Sci U S A 2020 Apr 28;117(17):9241-9243 [FREE Full text] [doi: [10.1073/pnas.2004999117](https://doi.org/10.1073/pnas.2004999117)] [Medline: [32269081](https://pubmed.ncbi.nlm.nih.gov/32269081/)]
4. Chookajorn T. Evolving COVID-19 conundrum and its impact. Proc Natl Acad Sci U S A 2020 Jun 09;117(23):12520-12521 [FREE Full text] [doi: [10.1073/pnas.2007076117](https://doi.org/10.1073/pnas.2007076117)] [Medline: [32381737](https://pubmed.ncbi.nlm.nih.gov/32381737/)]
5. Sánchez-Pacheco SJ, Kong S, Pulido-Santacruz P, Murphy RW, Kubatko L. Median-joining network analysis of SARS-CoV-2 genomes is neither phylogenetic nor evolutionary. Proc Natl Acad Sci U S A 2020 Jun 09;117(23):12518-12519 [FREE Full text] [doi: [10.1073/pnas.2007062117](https://doi.org/10.1073/pnas.2007062117)] [Medline: [32381733](https://pubmed.ncbi.nlm.nih.gov/32381733/)]
6. Mavian C, Pond SK, Marini S, Magalis BR, Vandamme AM, Dellicour S, et al. Sampling bias and incorrect rooting make phylogenetic network tracing of SARS-COV-2 infections unreliable. Proc Natl Acad Sci U S A 2020 Jun 09;117(23):12522-12523 [FREE Full text] [doi: [10.1073/pnas.2007295117](https://doi.org/10.1073/pnas.2007295117)] [Medline: [32381734](https://pubmed.ncbi.nlm.nih.gov/32381734/)]
7. Mavian C, Marini S, Prospero M, Salemi M. A Snapshot of SARS-CoV-2 Genome Availability up to April 2020 and its Implications: Data Analysis. JMIR Public Health Surveill 2020 Jun 1;6(2):e19170 [FREE Full text] [doi: [10.2196/19170](https://doi.org/10.2196/19170)] [Medline: [32412415](https://pubmed.ncbi.nlm.nih.gov/32412415/)]

8. MacLean O, Orton RJ, Singer JB, Robertson DL. No evidence for distinct types in the evolution of SARS-CoV-2. *Virus Evol* 2020 Jan;6(1):veaa034 [FREE Full text] [doi: [10.1093/ve/veaa034](https://doi.org/10.1093/ve/veaa034)] [Medline: [32817804](https://pubmed.ncbi.nlm.nih.gov/32817804/)]
9. Worobey M, Pekar J, Larsen BB, Nelson MI, Hill V, Joy JB, et al. The emergence of SARS-CoV-2 in Europe and North America. *Science* 2020 Sep 10. [doi: [10.1126/science.abc8169](https://doi.org/10.1126/science.abc8169)] [Medline: [32912998](https://pubmed.ncbi.nlm.nih.gov/32912998/)]
10. Ferretti L, Wymant C, Kendall M, Zhao L, Nurtay A, Abeler-Dörner L, et al. Quantifying SARS-CoV-2 transmission suggests epidemic control with digital contact tracing. *Science* 2020 May 08;368(6491) [FREE Full text] [doi: [10.1126/science.abb6936](https://doi.org/10.1126/science.abb6936)] [Medline: [32234805](https://pubmed.ncbi.nlm.nih.gov/32234805/)]
11. Salemi M, Vandamme AM, Lemey P. *The Phylogenetic Handbook: A Practical Approach to Phylogenetic Analysis and Hypothesis Testing*. Cambridge, UK: Cambridge University Press; 2009.

Edited by T Sanchez, T Derrick; submitted 29.09.20; this is a non-peer-reviewed article; accepted 01.10.20; published 11.11.20.

Please cite as:

Mavian C, Marini S, Prospero M, Salemi M

Authors' Reply to: Errors in Tracing Coronavirus SARS-CoV-2 Transmission Using a Maximum Likelihood Tree. Comment on "A Snapshot of SARS-CoV-2 Genome Availability up to April 2020 and its Implications: Data Analysis"

JMIR Public Health Surveill 2020;6(4):e24661

URL: <https://publichealth.jmir.org/2020/4/e24661>

doi: [10.2196/24661](https://doi.org/10.2196/24661)

PMID: [33174844](https://pubmed.ncbi.nlm.nih.gov/33174844/)

©Carla Mavian, Simone Marini, Mattia Prospero, Marco Salemi. Originally published in JMIR Public Health and Surveillance (<http://publichealth.jmir.org>), 11.11.2020. This is an open-access article distributed under the terms of the Creative Commons Attribution License (<https://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in JMIR Public Health and Surveillance, is properly cited. The complete bibliographic information, a link to the original publication on <http://publichealth.jmir.org>, as well as this copyright and license information must be included.

Original Paper

Outcomes of the Deployment of the Auto-Visual Acute Flaccid Paralysis Detection and Reporting (AVADAR) System for Strengthening Polio Surveillance in Africa From 2017 to 2018: Evaluation Study

Johnson Muluh Ticha^{1*}, MPH, MD; Godwin Ubong Akpan^{1*}, BEng, MSc, PhD; Lara MF Paige^{2*}, BA; Kamel Senouci², MD; Andrew Stein², BSc, MPH; Patrick Briand³, BSc; Jude Tuma⁴, MPH, PhD; Daniel Rasheed Oyaole⁵, BSc, MSc; Reuben Ngofa¹, BSc, MSc; Sylvester Maleghemi⁶, MSc, MD; Kebba Touray¹, BSc, MSc; Abdullahi Ahmed Salihu⁵, MPH, MD; Mamadou Diallo¹, BSc; Sisay Gashu Tegegne⁵, MPH, MD; Isah Mohammed Bello¹, BSc, MSc; Umar Kabo Idris⁵, BSc, MPH; Omosivie Maduka⁷, MPH, MD; Casimir Manengu¹, MPH, MD; Faisal Shuaib⁸, MPH, MD, PhD; Michael Galway², MSc; Pascal Mkanda¹, MPH, MD

¹World Health Organization Regional Office for Africa, Brazzaville, Congo

²Bill and Melinda Gates Foundation, Seattle, WA, United States

³Novel-T Sarl, Geneva, Switzerland

⁴World Health Organization, Geneva, Switzerland

⁵World Health Organization, Abuja, Nigeria

⁶World Health Organization South Sudan Office, Juba, South Sudan

⁷University of Port Harcourt, Port Harcourt, Nigeria

⁸National Primary Health Care Delivery Agency (NPHCDA), Abuja, Nigeria

* these authors contributed equally

Corresponding Author:

Godwin Ubong Akpan, BEng, MSc, PhD
World Health Organization Regional Office for Africa
Cite Du Djoue
Brazzaville, 500101
Congo
Phone: 242 055736476
Fax: 242 055736476
Email: akpang@who.int

Abstract

Background: As we move toward a polio-free world, the challenge for the polio program is to create an unrelenting focus on smaller areas where the virus is still present, where children are being repeatedly missed, where immunity levels are low, and where surveillance is weak.

Objective: This article aimed to describe a possible solution to address weak surveillance systems and document the outcomes of the deployment of the Auto-Visual Acute Flaccid Paralysis Detection and Reporting (AVADAR) project.

Methods: This intervention was implemented in 99 targeted high-risk districts with concerns for silent polio circulation from eight countries in Africa between August 1, 2017, and July 31, 2018. A total of 6954 persons (5390 community informants and 1564 health workers) were trained and equipped with a smartphone on which the AVADAR app was configured to allow community informants to send alerts on suspected acute flaccid paralysis (AFP) and allow health worker to use electronic checklists for investigation of such alerts. The AVADAR and Open Data Kit ONA servers were at the center of the entire process. A dashboard system and coordination teams for monitoring and supervision were put in place at all levels.

Results: Overall, 96.44% (24,142/25,032) of potential AFP case alerts were investigated by surveillance personnel, yielding 1414 true AFP cases. This number (n=1414) reported through AVADAR was higher than the 238 AFP cases expected during the study period in the AVADAR districts and the 491 true AFP cases reported by the traditional surveillance system. A total of

203 out of the 1414 true AFP cases reported were from special population settings, such as refugee camps and insecure areas. There was an improvement in reporting in silent health areas in all the countries using the AVADAR system. Finally, there were 23,473 reports for other diseases, such as measles, diarrhea, and cerebrospinal meningitis, using the AVADAR platform.

Conclusions: This article demonstrates the added value of AVADAR to rapidly improve surveillance sensitivity. AVADAR is capable of supporting countries to improve surveillance sensitivity within a short interval before and beyond polio-free certification.

(*JMIR Public Health Surveill* 2020;6(4):e18950) doi:[10.2196/18950](https://doi.org/10.2196/18950)

KEYWORDS

Auto-Visual Acute Flaccid Paralysis Detection and Reporting; surveillance; informants; acute flaccid paralysis; smartphones; polio

Introduction

Cases of paralysis caused by poliovirus have decreased by 99% since the World Health Assembly's resolution to eradicate polio [1]. The World Health Organization (WHO) recommends that a sensitive acute flaccid paralysis (AFP) surveillance system network should detect at least one case of nonpolio AFP annually per 100,000 children under 15 years of age. In addition, performance indicators for AFP surveillance require that reporting be timely and complete, and represent the geography of the country. [2]. All cases of AFP should be investigated and two stool samples should be collected from each AFP case at least 24 hours apart for viral isolation in a WHO-accredited laboratory [2]. The quality of AFP surveillance is therefore critical in countries moving toward the final phases of polio eradication [3]. Some countries in the African region have challenges with surveillance performance especially in security-challenged areas. For increasing AFP detection rates, innovations can be used to address challenges to the surveillance system and improve reporting in areas where key indicators of AFP surveillance are not being met, where surveillance is not being performed systematically, and where access to communities is a challenge. Studies have shown that the use of mobile technology for health in developing countries is an innovative and cost-effective approach to reach populations in low-resource settings [4]. Mobile phones are increasingly accessible worldwide [5]. In sub-Saharan Africa, the penetration of cell phones was estimated to be 63% in 2013 and projected to be more than 70% by 2015 [5]. Although mobile phone-based surveillance has the potential to provide real-time validated data for disease clustering and prompt response and investigation, little evidence is available on the current practice in sub-Saharan Africa [6]. In 2016, Shuiab et al demonstrated the use of an SMS text messaging-based technology app on smartphones called Auto-Visual AFP Detection and Reporting (AVADAR) that was given to health workers and community informants to improve the reporting of AFP in Nigeria [2]. Improvement in AFP reporting was observed in the pilot districts of Kuje and Oyun, demonstrating the added value of utilizing the AVADAR tool. With these initial positive results, AVADAR was implemented by the WHO Regional Office for Africa and used in 99 districts in Cameroon, Chad, the Democratic Republic of Congo, Liberia, Sierra Leone, South Sudan, and Niger, with technical support from the partner agencies Novel-T and eHealth Africa and funding provided by the Bill and Melinda Gates Foundation. The aim of this study was to determine the

outcomes of the deployment of AVADAR for enhanced surveillance and reporting in these districts.

Methods

Selection of Countries

Eight countries were enrolled into the AVADAR system. The inclusion criteria were based on polio risk analysis performed from 2016 to 2018, which prioritized the following criteria for targeted surveillance interventions: endemicity for polio (Nigeria), countries with districts in the Lake Chad basin area (Cameroon, Chad, and Niger), history of recent Ebola virus disease (Sierra Leone and Liberia), and areas with insecurity and hard to reach populations (South Sudan and the Democratic Republic of Congo). Selection of countries was carried out by the WHO Regional Office in Africa in collaboration with the country governments.

Selection of Districts

In each of the selected countries, a limited number of the highest risk districts for polio transmission were selected. The inclusion criteria used were as follows: weak surveillance system (as evidenced by a low nonpolio AFP rate; <2 for 100,000 children aged less than 15 years), existence of a telecommunications network in the community, presence of literate community members, presence of displaced populations or security challenges, and acceptance of the host governments for the use of technology in health. Selection was carried out by the health district authorities under supervision of the provincial and national health authorities in each country through final approval by the WHO Regional Office. An average of three to four districts were engaged per country. A total of 99 districts were included in the study

Selection of Community Informants

An average of 130 to 150 informants were selected per health district. Informants were selected by district-level health authorities in collaboration with local community leaders. Informants were listed by the health areas where they lived, and efforts were made to ensure that informants were evenly spread across all the health areas. Informants were expected to be able to read and write at a basic school level, have previous field experience in immunization activities including polio eradication, be able to manipulate a mobile phone, and accept being part of the project. In Chad and Cameroon, there were a high number of informants located in critical geographies for polio surveillance, who were unable to read or write. They were,

however, able to recognize a suspected case of AFP. Thus, these “special informants” were recruited and included in the project. The final list was then uploaded on the AVADAR server to monitor reporting by the informants. All informants were geo-located through “zero reporting” and “home reporting” on their mobiles. Zero reporting was done weekly by all informants enrolled in the system for not finding any child with AFP [7] ([Multimedia Appendix 1](#)). Home reporting was done once after the informant was enrolled in the AVADAR system. The informant clicked an icon when at home, which automatically recorded the map position, and the information was stored on the AVADAR server. This served to display the geographic spread of informants in the health areas or districts selected for the AVADAR project, as well as the expected location (within a certain geographic range) where future reports would come from, although a community informant could report an alert beyond this geography.

Selection of Health Workers

Health workers were selected in the same health areas and districts from where community informants were selected. One health worker was selected for every 10 community informants. Health workers (members of the existing surveillance system) were defined as those within a community with good experience in AFP surveillance or polio eradication activities and were motivated to conduct field investigations on suspected AFP cases (alerts). The health workers and informants were not paid. However, they were provided with air time (talk time) and data to send the weekly reports, and transportation costs to investigate alerts on suspected AFP cases were covered by the program.

Training

A 2-day national training of trainers was organized in each country to inform, sensitize, and train central-level health authorities on the AVADAR system. This was followed by another 2-day training of health workers and informants on the AVADAR app with practical demonstrations, using the repetitive training methodology to ensure that both informants and health workers were fully aware of the alerting and investigation process and could function independently [8,9].

Pilot Testing of the AVADAR System

The AVADAR system was piloted in two districts in Nigeria in 2016. The lessons learned from the pilot testing were used to improve checklists and selection of participants and to refine the training methodology. Various processes were thus adapted to country contexts as per health system requirements in terms of terminology and norms [10].

AVADAR Servers and Investigation of Alerts

The actors in the AVADAR system (informants and health workers) were configured in the AVADAR server. On a weekly basis, the server auto-played the AFP case definition video. Each informant was expected to respond in order to confirm that he/she is still in the system. This was called a zero report. When an informant submitted a report, the report was assigned a unique number called report submission identification and an alert was sent to the AVADAR server. The AVADAR server then sent an automated SMS text message to health workers' phones. On average, 10 health workers were configured to

receive an SMS from the server for every AFP alert from an informant to ensure correct tracking and investigation of all alerts. Upon receipt of the SMS, the health worker and the informant could use the closed user group (CUG) telecommunications feature to further discuss the report. CUG is a network of SIM cards with unlimited access to make free phone calls to other SIM cards within the network. AVADAR informants and health workers investigating alerts were members of the CUG. A health worker traveled to investigate the case. Once the investigation was completed and the report was uploaded to the server, an SMS text message or email was sent from the server to preselected stakeholders to receive the findings of the investigation. As soon as the health worker confirmed that the alert investigated was a true AFP, further investigations were performed, leading to the collection of stool samples. In parallel, a second server (Open Data Kit [ODK]) received the same SMS text message. This ODK server has been designed to display some key predetermined outputs in the form of indicators.

Data Collection and Use

A simple electronic questionnaire was developed and deployed on the smartphone of each informant. This enabled ease of use of the AVADAR app when a case was suspected by recording few key variables. These variables included the name of the suspected case (alert), location, and duration from onset to detection. Submission of the questionnaire to the server was by a simple click.

Similarly, two electronic checklists for health workers were built using ODK and downloaded onto their smartphones. One checklist collected data during investigation of alerts sent by informants. This is a critical stage in the AVADAR system because the alerts being investigated may turn out to be true AFPs. Once an investigation was completed, the checklist was uploaded to the sever. A trigger generated by the server was sent to a determined number of persons situated at the district, province, nation, or beyond. This trigger was a reminder that an alert has been investigated, and if the alert was a true AFP, follow-up was needed to ensure that a field investigation of the case was conducted timely. The second checklist for health workers on ODK was used to collect data during supervision of AVADAR activities.

AVADAR Dashboard

The AVADAR dashboard reconciled all the soft documentation of alerts and investigations and evaluated the performance of the surveillance system in real time. This dashboard was an output of the reconciliation of the AVADAR server, which housed all informant reporting (zero and suspected AFP reporting) and the ODK server (the actual investigation by health workers). This dashboard made available in real time the status of all AFP alerts and investigations done via AVADAR from the country level to the ward/settlement level. It also assisted stakeholders to immediately assess where supervisory activities should be focused.

Monitoring the Implementation of AVADAR

A major feature of AVADAR is that the platform is useful for monitoring the implementation of surveillance processes and

activities in high-risk areas. In each AVADAR district, there was a coordination team consisting of an AVADAR coordinator from WHO, an eHealth technical coordinator, and a Ministry of Health focal person. This same structure existed at the ward level (health area) where the head of the health area coordinated all AVADAR activities. Monthly meetings were organized by the Ministry of Health with support from WHO and eHealth to monitor activity implementation and progress, and to solve problems related to smartphone functionality and chargers. National-, provincial-, and district-level officers conducted regular supportive supervisory visits for the various community informants to ensure that activities were being implemented as planned and to resolve challenges. The WHO Regional Office had regular teleconferences with countries, conducted field visits, and organized an annual review and planning meeting bringing together various stakeholders with objectives to foster program coordination and performance [11].

Ethical Approval and Consent to Participate

Approval from an ethics committee and consent to participate were not required for analyses based solely on secondary data.

Table 1. Human capital and smartphones engaged for the Auto-Visual Acute Flaccid Paralysis Detection and Reporting (AVADAR) project in eight countries from August 1, 2017, to July 31, 2018.

Country	Community informants (N=5228), n (%)	Special informants (N=162), n (%)	Total informants (N=5390), n (%)	Health workers (N=1564), n (%)	Total (N=6954), n (%)
Nigeria	2418 (46.25%)	0 (0.00%)	2418 (44.86%)	874 (55.88%)	3292 (47.34%)
Chad	441 (8.44%)	104 (64.20%)	545 (10.11%)	77 (4.92%)	622 (8.94%)
Cameroon	552 (10.56%)	28 (17.28%)	580 (10.76%)	108 (6.91%)	688 (9.89%)
Niger	471 (9.01%)	30 (18.52%)	501 (9.29%)	133 (8.50%)	634 (9.12%)
Liberia	288 (5.51%)	0 (0.00%)	288 (5.34%)	114 (7.28%)	402 (5.78%)
Sierra Leone	405 (7.75%)	0 (0.00%)	405 (7.51%)	98 (6.27%)	503 (7.23%)
Democratic Republic of Congo	402 (7.69%)	0 (0.00%)	402 (7.46%)	135 (8.63%)	537 (7.72%)
South Sudan	251 (4.80%)	0 (0.00%)	251 (4.66%)	25 (1.59%)	276 (3.97%)

A total of 162 special informants were engaged in three countries (Chad, Cameroon, and Niger) (Table 1). The special informants represented 2.33% (n=6954) of all informants engaged in the eight countries. The special informants in Chad constituted 16.7% (n=104) of all community informants engaged in the country (N=622). In Cameroon, the special informants represented 4.1% (n=28) of all informants in the country (N=688), and in Niger, the special informants represented 4.7% (n=30) of all informants engaged in the country (N=634). There was no difference in reporting alerts from both community informants and special informants.

Within the 12 months of the study, a total of 433,601 reports were expected to be sent by informants through weekly reports (also called zero reports) to indicate they were still in the network, and of these, 64.66% (280,376) were received (Table

Results

A total of 5390 informants were engaged in the AVADAR project in the eight countries from August 1, 2017, to July 31, 2018. Of the 5390 informants, 96.99% (n=5228) were community informants and 3.01% (n=162) were special informants (Table 1). The number of community informants who participated in the AVADAR system was dependent upon the number of health areas. Nigeria, which deployed AVADAR in 54 health districts, had 44.86% (n=2418) of the total informants, while South Sudan, which deployed AVADAR in three health districts, had 4.66% (n=251) of the total community informants. Similarly, a total of 1564 health workers were engaged in the project in the eight countries. The health workers engaged in Nigeria represented 55.88% (n=874) of the total health workers in the project, while those engaged in South Sudan represented 1.59% (n=25) of the health workers.

2). Each informant reported once a week for the 52 weeks of the study period. Of the reports received, 65% (280,376) were received timely (within 48 h). The highest proportion of reports were received from South Sudan, where 92.58% (3932/4247) of informants actively responded to the weekly calls. This was followed by Niger, with 79.61% (18,498/23,236). The least active country was Nigeria, with just 57.31% (135,129/235,767) of reports received. With regard to alerts sent to the server on suspected AFP cases, a total of 25,032 were received, and 96.44% (24,142) of these were investigated.

Of these 24,142 alerts investigated, 5.86% (1414) yielded true AFP cases. This yield varied across countries, with the highest yield of 24.70% (589/2385) in Nigeria, followed by 16.84% (33/196) in South Sudan. Chad and Liberia both had the lowest yields of 0.98% (119/12,103) and 0.93% (15/1615), respectively.

Table 2. Performance of the Auto-Visual Acute Flaccid Paralysis Detection and Reporting (AVADAR) system compared with the traditional system of reporting acute flaccid paralysis cases from August 1, 2017, to July 31, 2018.

Country	Expected number of reports	Total number of reports received	Completeness (%) of reports received	Expected number of alerts investigated	Number of Investigations done	Investigation (%) of alerts received	Expected number of AVADAR ^a AFP ^b cases	Number of AVADAR AFP cases	Proportion (%) of AVADAR AFP cases	Expected annual number of AFP cases in AVADAR districts	Number of AFP cases reported by the traditional surveillance system
Nigeria	235,767	135,129	57.31	2562	2385	93.09	2385	589	24.70	45	279
Chad	35,558	22,833	64.21	12,321	12,103	98.23	12,103	119	0.98	23	48
Cameroon	37,266	26,880	72.13	2050	1946	94.93	1946	96	4.93	40	34
Niger	23,236	18,498	79.61	1005	986	98.11	986	103	10.45	24	85
Liberia	29,051	19,855	68.35	1888	1615	85.54	1615	15	0.93	20	0
Sierra Leone	38,009	32,667	85.95	416	393	94.47	393	27	6.87	16	15
Democratic Republic of Congo	30,467	20,582	67.55	4593	4518	98.37	4518	432	9.56	56	24
South Sudan	4247	3932	92.58	197	196	99.49	196	33	16.84	14	6
All countries	433,601	280,376	64.66	25,032	24,142	96.44	24,142	1414	5.86	238	491

^aAVADAR: Auto-Visual Acute Flaccid Paralysis Detection and Reporting.

^bAFP: acute flaccid paralysis.

With regard to the AFP yield, a total of 238 AFPs were expected from AVADAR districts within the study period. In terms of this number, 491 (206.1%) AFPs were reported by the traditional AFP system and 1414 (591.1%) AFPs were reported through the AVADAR system. It is important to note that an AFP was attributed to the system that first reported the case (either the AVADAR or traditional system) to avoid double counting of cases.

As shown in [Table 3](#), from 2016 to 2018, there were 381 silent wards as the AVADAR intervention took off in different countries. After the stabilization of the intervention, in 2018, there was a 100% reduction in silent health areas in the Democratic Republic of Congo and Liberia. In absolute terms, there was improvement in reporting across all countries, with the lowest evidence-based improvement being in Chad (32%). This further supports AFP surveillance intensification that AVADAR elaborates, leading to reduction in silent areas [12].

Table 3. Impact of Auto-Visual Acute Flaccid Paralysis Detection and Reporting (AVADAR) in eight countries on the reduction in silent health areas in 2016-2018 compared with 2019 (aggregated comparison).

Country	Maximum number of silent wards in 2016-2018	Number of silent wards in 2019	Percentage reduction in silent wards in 2019
Cameroon	58	27	53%
Chad	63	43	32%
Democratic Republic of Congo	43	0	100%
Liberia	1	0	100%
Niger	19	10	47%
Sierra Leone	40	25	38%
South Sudan	12	5	58%
Nigeria	145	49	66%
All AVADAR ^a countries	381	159	58%

^aAVADAR: Auto-Visual Acute Flaccid Paralysis Detection and Reporting.

Considering the traditional AFP cases reported, the AVADAR cases, and the silent district reduction reported in the same period ([Table 2](#) and [Table 3](#)), we have provided the *P* values

for comparisons in [Table 4](#). We ran paired sample *t* tests on information in [Table 2](#) for comparing AVADAR cases and traditional AFP cases ([Table 2](#) column 9 [numbers: 589, 119,

96, 103, 15, 27, 432, and 33] vs column 12 [numbers: 279, 48, 34, 85, 0, 15, 24, and 6]), and obtained $P=.07$ (two-tailed) and $P=.04$ (one-tailed), using Microsoft Excel 2016 (Microsoft Corporation).

We also ran paired sample t tests on information in Table 3 for the silent ward reduction (Table 3 column 2 [numbers: 58, 63, 43, 1, 19, 40, 12, 145, and 381] vs column 3 [numbers: 27, 43, 0, 0, 10, 25, 5, 49, and 159]) and obtained $P=.07$ (two-tailed) and $P=.04$ (one-tailed), using Microsoft Excel 2016.

Table 4. Comparison of mean, standard deviation, and P value of the Auto-Visual Acute Flaccid Paralysis Detection and Reporting (AVADAR) system and traditional surveillance system regarding acute flaccid paralysis reporting and silent wards (2017-2018).

Variable	Number of AVADAR ^a AFP ^b cases	Number of AFP cases reported by the traditional surveillance system	Maximum number of silent wards in 2016-2018	Number of silent wards in 2019
Mean	314.2222222	109.1111111	84.66666667	35.33333333
Variance	210043.6944	27912.11111	14119.75	2471.75
Observations	9	9	9	9
Pearson correlation	0.944806625	N/A ^c	0.979342284	N/A
Hypothesized mean difference	0	N/A	0	N/A
df	8	N/A	8	N/A
t stat	2.014828247	N/A	2.088810505	N/A
P ($T \leq t$) one-tailed	0.039343527	N/A	0.035073851	N/A
t critical one-tailed	1.859548038	N/A	1.859548038	N/A
P ($T \leq t$) two-tailed	0.078687054	N/A	0.070147702	N/A
t critical two-tailed	2.306004135	N/A	2.306004135	N/A

^aAVADAR: Auto-Visual Acute Flaccid Paralysis Detection and Reporting.

^bAFP: acute flaccid paralysis.

^cN/A: not applicable.

A total of 203 AFP cases were reported in special populations, of which 44.3% ($n=90$) were from internally displaced persons/refugees (Table 5). Approximately 7.8% ($n=43$) of the cases reported from internally displaced persons/refugees were from Nigeria owing to a high number of internally displaced person/refugee camps in AVADAR districts in Nigeria. A total

of 72% (31/43) of cases reported from Nomads were from Chad. Chad has nomadic populations in all the six AVADAR districts. A total of 90% (63/70) of cases reported from areas of insecurity were reported from Nigeria that runs AVADAR in 54 local government areas with security challenges.

Table 5. Acute flaccid paralysis reported through Auto-Visual Acute Flaccid Paralysis Detection and Reporting (AVADAR) in special population settings (August 1, 2017, to July 31, 2018).

Country/special population	Number of AFP ^a cases reported from IDPs ^b /refugees (N=90), n (%)	Number of AFP cases reported from Nomads (N=43), n (%)	Number of AFP cases reported from insecure areas (N=70), n (%)	Total (N=203), n (%)
Nigeria	43 (48%)	4 (9%)	63 (90%)	110 (54%)
Chad	0 (0%)	31 (72%)	0 (0%)	31 (15%)
Cameroon	16 (18%)	0 (0%)	5 (7%)	21 (10%)
Niger	31 (34%)	8 (19%)	0 (0%)	39 (19%)
South Sudan	0 (0%)	0 (0%)	2 (3%)	2 (1%)

^aAFP: acute flaccid paralysis.

^bIDP: internally displaced person.

Using the CUG network, informants were able to report other disease conditions apart from AFP. Nigeria reported the highest number of suspected measles cases (587/902, 65%) and

suspected cerebrospinal meningitis cases (182/194, 93.8%). Similarly, the Democratic Republic of Congo reported 19,419 cases (86.8%, $N=22,377$) of acute watery disease (Table 6).

Table 6. Other disease conditions reported by Auto-Visual Acute Flaccid Paralysis Detection and Reporting (AVADAR) informants (August 1, 2017, to July 31, 2018).

Country	Number of suspected measles cases (N=902), n (%)	Number of acute watery disease cases (N=22,377), n (%)	Number of suspected cerebrospinal meningitis cases (N=194), n (%)	Total (N=23,473), n (%)
Nigeria	587 (65.1%)	1232 (5.5%)	182 (93.8%)	2001 (8.5%)
Chad	117 (13.0%)	133 (0.6%)	0 (0.0%)	250 (1.1%)
Liberia	60 (6.7%)	1550 (6.9%)	0 (0.0%)	1610 (6.9%)
Democratic Republic of Congo	133 (14.7%)	19,419 (86.8%)	12 (6.2%)	19,564 (83.3%)
South Sudan	5 (0.6%)	43 (0.2%)	0 (0.0%)	48 (0.2%)

Discussion

Principal Findings

We found a marked increase in the number of cases of AFP reported through the AVADAR system compared with those reported through the traditional system in the same districts within the same period. These findings are similar to those of Shuaib et al in the AVADAR pilot study in Kwara and Kuje LGAs in 2016 [2]. We also demonstrated that 14.36% (203/1414) of AFP cases were from areas with security challenges or from special populations. It is likely that without AVADAR, these cases would have been missed. In 2017, in a study on the use of mHealth in polio eradication and other immunization activities in developing countries, Kim et al concluded that growing access to technology and widespread mobile connectivity offer a tremendous opportunity for the immunization community to leverage these efforts to improve and sustain immunization services, particularly for populations currently not reached and at the highest risk of vaccine preventable diseases [13]. Other studies have also demonstrated the usefulness of several mHealth interventions for improved health care delivery at all levels of care and even under unfavorable security and economic conditions [14].

We also found statistical significance ($P=.04$) when comparing AVADAR AFP cases and traditional AFP cases for the period under review.

This study also demonstrated a marked reduction in silent health areas and districts in all the countries where AVADAR was deployed. This reduction in silent health areas was more significant in the Democratic Republic of Congo and Liberia. We also did a paired two samples test for means of silent wards before AVADAR and after AVADAR, which revealed reduction of silent districts based on the introduction of AVADAR at the district level. The output of the paired T sample analyses indicated that the mean for the silent districts before AVADAR/introduction of AVADAR was 84.67 and after AVADAR was 35.33. For our results, we used P ($T \leq t$) two-tailed, which is the P value for the two-tailed form of the t test. Because our P value (.03) was less than the standard significance level of .05, we could reject the null hypothesis. Our sample data support the hypothesis that the before and after AVADAR silent district means are different.

The use of technology has been shown to improve health worker accountability and reporting. This is partly due to the removal of reporting barriers and the monitoring and peer review role of technology for improving data quality and reporting [15,16]. These qualities make AVADAR and other mHealth innovations useful for improving health outcomes [17].

The successful use of community informants and special informants indicates that AVADAR and other mHealth innovations when correctly deployed can be used even by nonhealth workers. The AVADAR program has a simplified case definition and has user-friendly forms and questionnaires suitable for nonhealth personnel. The departure from health worker-dependent surveillance to involving community informants has been shown to improve the quality and effectiveness of surveillance activities, especially in security-challenged locations [18].

We also found out that other disease conditions, such as measles, acute watery disease, and cerebrospinal meningitis, were reported through AVADAR. This is an indication that this community-based initiative (AVADAR) has the potential to report other disease conditions in a timely manner to trigger a timely response. Though AVADAR was originally designed for AFP surveillance, the platform could be used for other disease surveillance, demonstrating the use of the AVADAR platform beyond poliomyelitis eradication certification. This implies that the same infrastructure that supports AVADAR can be deployed to support other disease surveillance activities across countries. This makes the AVADAR system a robust and cost-effective solution [2].

The strength of this study is that it demonstrates the usefulness and impact of an mHealth solution like AVADAR at scale. This is unlike many other studies that only showed success with pilot studies or studies with small sample sizes and confined populations [6,19,20]. AVADAR is therefore proven to be a promising strategy for countries facing weak surveillance systems related to insecurity or those with hard-to-reach populations.

Limitations

The use of AVADAR is limited by the weak telecommunication infrastructure in most countries, notably in rural and remote areas, which are the most suited for its application. Second, the system is relatively costly and thus heavily reliant on funding. Despite these limitations, AVADAR could be recommended in

areas with surveillance gaps and challenges. However, government ownership and domestic funding are required to ensure sustainability.

Conclusions

The marked increase in the case detection of AFP justifies the cost-intensive nature of the intervention. The system is relatively costly and thus heavily reliant on funding. Despite the high cost, AVADAR could be recommended in areas with surveillance gaps and challenges. However, government ownership and domestic funding are required to ensure sustainability.

AVADAR is recommended beyond the Global Polio Eradication Initiative program for broader public health initiatives and strengthening of health systems. The potential to keep on using the structure set up with minimal additional infrastructure cost also makes this intervention a worth-while solution for enhanced surveillance and control of communicable and noncommunicable diseases.

Within a 12-month period, AVADAR showed a positive impact by improving AFP surveillance performance to certification standards. Achieving certification standards remains a key requirement for all districts, and the African region achieved a wild polio-free status on August 25, 2020.

Acknowledgments

We thank the different Country Ministries of Health, community informants, and health workers who have continuously made the polio eradication agenda a personal mission. The authors alone are responsible for the views expressed in this article, which do not necessarily represent the views, decisions, or policies of the institutions with which they are affiliated.

Authors' Contributions

JT and AG conceived and wrote the first draft of the manuscript. All authors read and provided important inputs for all drafts of the manuscript, agreed to be accountable for all aspects of the work, and approved the final draft of the manuscript for publication.

Conflicts of Interest

None declared.

Multimedia Appendix 1

AVADAR video for stimulating and reminding Diseases Notification Officers to conduct active surveillance and submit weekly AFP or Zero reporting.

[MP4 File (MP4 Video), 17506 KB - [publichealth_v6i4e18950_app1.mp4](#)]

References

1. Johnson Muluh T, Hamisu AW, Craig K, Mkanda P, Andrew E, Adeniji J, et al. Contribution of Environmental Surveillance Toward Interruption of Poliovirus Transmission in Nigeria, 2012-2015. *J Infect Dis* 2016 May 01;213 Suppl 3(suppl 3):S131-S135 [FREE Full text] [doi: [10.1093/infdis/jiv767](#)] [Medline: [26908747](#)]
2. Shuaib FM, Musa PF, Gashu ST, Onoka C, Ahmed SA, Bagana M, et al. AVADAR (Auto-Visual AFP Detection and Reporting): demonstration of a novel SMS-based smartphone application to improve acute flaccid paralysis (AFP) surveillance in Nigeria. *BMC Public Health* 2018 Dec 13;18(Suppl 4):1305 [FREE Full text] [doi: [10.1186/s12889-018-6187-x](#)] [Medline: [30541508](#)]
3. Isibor I, Gasasira A, Mkanda P, Weldegriberiel G, Basse B, Toritseju M, et al. Rapid assessments of acute flaccid paralysis surveillance in seven key polio high risk states in Northern Nigeria. *Peak J Med Med Sci* 2014;2(3):33-40.
4. Maduka O, Akpan G, Maleghemi S. Using Android and Open Data Kit Technology in Data Management for Research in Resource-Limited Settings in the Niger Delta Region of Nigeria: Cross-Sectional Household Survey. *JMIR Mhealth Uhealth* 2017 Nov 30;5(11):e171 [FREE Full text] [doi: [10.2196/mhealth.7827](#)] [Medline: [29191798](#)]
5. Betjeman TJ, Soghoian SE, Foran MP. mHealth in Sub-Saharan Africa. *Int J Telemed Appl* 2013;2013:482324-482327 [FREE Full text] [doi: [10.1155/2013/482324](#)] [Medline: [24369460](#)]
6. Brinkel J, Krämer A, Krumkamp R, May J, Fobil J. Mobile phone-based mHealth approaches for public health surveillance in sub-Saharan Africa: a systematic review. *Int J Environ Res Public Health* 2014 Nov 12;11(11):11559-11582 [FREE Full text] [doi: [10.3390/ijerph111111559](#)] [Medline: [25396767](#)]
7. Zero Reporting. Oxford Reference. URL: <http://www.oxfordreference.com/view/10.1093/acref/9780199976720.001.0001/acref-9780199976720-e-1990> [accessed 2020-08-01]
8. Clara A, Do TT, Dao AT, Tran PD, Dang TQ, Tran QD, et al. Event-Based Surveillance at Community and Healthcare Facilities, Vietnam, 2016-2017. *Emerg Infect Dis* 2018 Sep;24(9):1649-1658 [FREE Full text] [doi: [10.3201/eid2409.171851](#)] [Medline: [30124198](#)]
9. Bosse HM, Mohr J, Buss B, Krautter M, Weyrich P, Herzog W, et al. The benefit of repetitive skills training and frequency of expert feedback in the early acquisition of procedural skills. *BMC Med Educ* 2015 Feb 19;15(1):22 [FREE Full text] [doi: [10.1186/s12909-015-0286-5](#)] [Medline: [25889459](#)]

10. Wright A, Aaron S, Sittig DF. Testing electronic health records in the "production" environment: an essential step in the journey to a safe and effective health care system. *J Am Med Inform Assoc* 2017 Jan 23;24(1):188-192 [FREE Full text] [doi: [10.1093/jamia/ocw039](https://doi.org/10.1093/jamia/ocw039)] [Medline: [27107450](https://pubmed.ncbi.nlm.nih.gov/27107450/)]
11. Pinzon-Perez H, Zelinski C. The role of teleconferences in global public health education. *Glob Health Promot* 2016 Jun;23(2):38-44 [FREE Full text] [doi: [10.1177/1757975914567180](https://doi.org/10.1177/1757975914567180)] [Medline: [25783439](https://pubmed.ncbi.nlm.nih.gov/25783439/)]
12. Umeh GC, Shuaib F, Musa A, Tegegne SG, Braka F, Mkanda P, et al. Acute flaccid paralysis (AFP) surveillance intensification for polio certification in Kaduna state, Nigeria: lessons learnt, 2015-2016. *BMC Public Health* 2018 Dec 13;18(Suppl 4):1310 [FREE Full text] [doi: [10.1186/s12889-018-6186-y](https://doi.org/10.1186/s12889-018-6186-y)] [Medline: [30541509](https://pubmed.ncbi.nlm.nih.gov/30541509/)]
13. Kim SS, Patel M, Hinman A. Use of m-Health in polio eradication and other immunization activities in developing countries. *Vaccine* 2017 Mar 07;35(10):1373-1379. [doi: [10.1016/j.vaccine.2017.01.058](https://doi.org/10.1016/j.vaccine.2017.01.058)] [Medline: [28190744](https://pubmed.ncbi.nlm.nih.gov/28190744/)]
14. Akpan G, Tegegne S, Erbetto T, Daramola O, Braka F, Mkanda P. Use of Mobile Phone and Facility-based Server Technology in Routine Immunization and Disease Surveillance Activities in Nigeriatrengthening Polio Surveillance. 2018 Presented at: 2018 International Conference on Smart Computing and Electronic Enterprise (ICSCEE); July 11-12, 2018; Shah Alam, Malaysia. [doi: [10.1109/ICSCEE.2018.8538406](https://doi.org/10.1109/ICSCEE.2018.8538406)]
15. Källander K, Tibenderana JK, Akpogheneta OJ, Strachan DL, Hill Z, ten Asbroek AH, et al. Mobile health (mHealth) approaches and lessons for increased performance and retention of community health workers in low- and middle-income countries: a review. *J Med Internet Res* 2013 Jan 25;15(1):e17 [FREE Full text] [doi: [10.2196/jmir.2130](https://doi.org/10.2196/jmir.2130)] [Medline: [23353680](https://pubmed.ncbi.nlm.nih.gov/23353680/)]
16. Braun R, Catalani C, Wimbush J, Israelski D. Community health workers and mobile technology: a systematic review of the literature. *PLoS One* 2013 Jun 12;8(6):e65772 [FREE Full text] [doi: [10.1371/journal.pone.0065772](https://doi.org/10.1371/journal.pone.0065772)] [Medline: [23776544](https://pubmed.ncbi.nlm.nih.gov/23776544/)]
17. Mechael PN. The Case for mHealth in Developing Countries. *Innovations: Technology, Governance, Globalization* 2009 Jan;4(1):103-118. [doi: [10.1162/itgg.2009.4.1.103](https://doi.org/10.1162/itgg.2009.4.1.103)]
18. Hamisu AW, Johnson TM, Craig K, Mkanda P, Banda R, Tegegne SG, et al. Strategies for Improving Polio Surveillance Performance in the Security-Challenged Nigerian States of Adamawa, Borno, and Yobe During 2009-2014. *J Infect Dis* 2016 May 01;213 Suppl 3(suppl 3):S136-S139 [FREE Full text] [doi: [10.1093/infdis/jiv530](https://doi.org/10.1093/infdis/jiv530)] [Medline: [26655842](https://pubmed.ncbi.nlm.nih.gov/26655842/)]
19. Shuaib FM, Musa PF, Gashu ST, Onoka C, Ahmed SA, Bagana M, et al. AVADAR (Auto-Visual AFP Detection and Reporting): demonstration of a novel SMS-based smartphone application to improve acute flaccid paralysis (AFP) surveillance in Nigeria. *BMC Public Health* 2018 Dec 13;18(Suppl 4):1305 [FREE Full text] [doi: [10.1186/s12889-018-6187-x](https://doi.org/10.1186/s12889-018-6187-x)] [Medline: [30541508](https://pubmed.ncbi.nlm.nih.gov/30541508/)]
20. Hall CS, Fottrell E, Wilkinson S, Byass P. Assessing the impact of mHealth interventions in low- and middle-income countries--what has been shown to work? *Glob Health Action* 2014 Oct 27;7(1):25606 [FREE Full text] [doi: [10.3402/gha.v7.25606](https://doi.org/10.3402/gha.v7.25606)] [Medline: [25361730](https://pubmed.ncbi.nlm.nih.gov/25361730/)]

Abbreviations

AFP: acute flaccid paralysis

AVADAR: Auto-Visual Acute Flaccid Paralysis Detection and Reporting

CUG: closed user group

ODK: Open Data Kit

WHO: World Health Organization

Edited by T Sanchez; submitted 02.04.20; peer-reviewed by T Gardner, G Umeh, F Yamin; comments to author 24.04.20; revised version received 19.06.20; accepted 03.08.20; published 02.12.20.

Please cite as:

Ticha JM, Akpan GU, Paige LMF, Senouci K, Stein A, Briand P, Tuma J, Oyaole DR, Ngofa R, Maleghemi S, Touray K, Salihu AA, Diallo M, Tegegne SG, Bello IM, Idris UK, Maduka O, Manengu C, Shuaib F, Galway M, Mkanda P

Outcomes of the Deployment of the Auto-Visual Acute Flaccid Paralysis Detection and Reporting (AVADAR) System for Strengthening Polio Surveillance in Africa From 2017 to 2018: Evaluation Study

JMIR Public Health Surveill 2020;6(4):e18950

URL: <http://publichealth.jmir.org/2020/4/e18950/>

doi:[10.2196/18950](https://doi.org/10.2196/18950)

PMID:[33263550](https://pubmed.ncbi.nlm.nih.gov/33263550/)

Gashu Tegegne, Isah Mohammed Bello, Umar Kabo Idris, Omosivie Maduka, Casimir Manengu, Faisal Shuaib, Michael Galway, Pascal Mkanda. Originally published in JMIR Public Health and Surveillance (<http://publichealth.jmir.org>), 02.12.2020. This is an open-access article distributed under the terms of the Creative Commons Attribution License (<https://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in JMIR Public Health and Surveillance, is properly cited. The complete bibliographic information, a link to the original publication on <http://publichealth.jmir.org>, as well as this copyright and license information must be included.

Original Paper

Barriers to Creating Scalable Business Models for Digital Health Innovation in Public Systems: Qualitative Case Study

Leah Taylor Kelley¹, BSc; Jamie Fujioka¹, MPH; Kyle Liang¹, MSc; Madeline Cooper¹, MSc; Trevor Jamieson², MD; Laura Desveaux^{1,3}, PhD

¹Institute for Health System Solutions and Virtual Care, Women's College Hospital, Toronto, ON, Canada

²Unity Health, Toronto, ON, Canada

³Institute of Health Policy, Management and Evaluation, University of Toronto, Toronto, ON, Canada

Corresponding Author:

Laura Desveaux, PhD

Institute for Health System Solutions and Virtual Care

Women's College Hospital

76 Grenville Street

Toronto, ON, M5S 1B2

Canada

Phone: 1 4163236400 ext 4302

Email: laura.desveaux@wchospital.ca

Abstract

Background: Health systems are increasingly looking toward the private sector to provide digital solutions to address health care demands. Innovation in digital health is largely driven by small- and medium-sized enterprises (SMEs), yet these companies experience significant barriers to entry, especially in public health systems. Complex and fragmented care models, alongside a myriad of relevant stakeholders (eg, purchasers, providers, and producers of health care products), make developing value propositions for digital solutions highly challenging.

Objective: This study aims to identify areas for health system improvement to promote the integration of innovative digital health technologies developed by SMEs.

Methods: This paper qualitatively analyzes a series of case studies to identify health system barriers faced by SMEs developing digital health technologies in Canada and proposed solutions to encourage a more innovative ecosystem. The Women's College Hospital Institute for Health System Solutions and Virtual Care established a consultation program for SMEs to help them increase their innovation capacity and take their ideas to market. The consultation involved the SME filling out an onboarding form and review of this information by an expert advisory committee using guided considerations, leading to a recommendation report provided to the SME. This paper reports on the characteristics of 25 SMEs who completed the program and qualitatively analyzed their recommendation reports to identify common barriers to digital health innovation.

Results: A total of 2 central themes were identified, each with 3 subthemes. First, a common barrier to system integration was the lack of formal evaluation, with SMEs having limited resources and opportunities to conduct such an evaluation. Second, the health system's current structure does not create incentives for clinicians to use digital technologies, which threatens the sustainability of SMEs' business models. SMEs faced significant challenges in engaging users and payers from the public system due to perverse economic incentives. Physicians are compensated by in-person visits, which actively works against the goals of many digital health solutions of keeping patients out of clinics and hospitals.

Conclusions: There is a significant disconnect between the economic incentives that drive clinical behaviors and the use of digital technologies that would benefit patients' well-being. To encourage the use of digital health technologies, publicly funded health systems need to dedicate funding for the evaluation of digital solutions and streamlined pathways for clinical integration.

(*JMIR Public Health Surveill* 2020;6(4):e20579) doi:[10.2196/20579](https://doi.org/10.2196/20579)

KEYWORDS

digital technologies; telemedicine; innovation diffusion; health policy; evaluation study; reimbursement; incentive; mobile phone

Introduction

Background

Digital technology offers the potential to efficiently meet the health care demands of a population growing in both size and complexity, without sacrificing quality. Administrators and health organizations are increasingly seeking technologies from the private health care market to achieve this aim [1]. Despite these efforts and accompanying investments [2], health systems struggle to translate innovation into clinical practice [3,4]. Failure to clearly define the health care marketplace and the parameters for entry present considerable challenges for private sector small- and medium-sized enterprises (SMEs) [5]. Maximizing value in public-private partnerships for digital health requires motivating the development of innovative solutions by the private industry, encouraging integration of those solutions into clinical spaces, and assuring ongoing refinement of the tools and surrounding clinical models [6].

Driving Innovation in Public Health Systems

Creating an environment in which emerging solutions meet the needs of a public health system requires that these private entities develop sustainable business models within that system [7]. However, health systems are characterized by complex and fragmented care models, alongside a myriad of regulatory models and incentive structures that are often incongruent with private sector business models [7]. Further, the ability to demonstrate value to public systems is challenging due to complex clinical practices, organizational processes, and provider workflows [8]. The issue of incentives and payment models to support the use of digital tools that promote patients' well-being cannot be solved through accelerators and academic medical centers. If health systems want to increase the use of digital tools that can reduce the use of health services and alleviate the burden on acute care facilities, there is a need for incentive models that support their adoption. Currently, digital models that rely on clinicians monitoring data are affected because this model has no economic incentive to encourage the clinician to participate and incurs a fear of liability [9]. Complex and often conflicting actors in health care (eg, purchasers, providers, and producers of health care products) make developing value propositions associated with those products highly challenging [10]. Electronic health records are a telling precedent, as health system payers implemented them to solve issues primarily for the payers, including data collection for administrators and billing, at times at the expense of clinician experience. This has led to feelings of frustration and burnout associated with their use [11]. Policy makers need to consider incentive models for innovators to develop products that support direct clinical needs *and* help solve system problems. There is a recognized need for health systems to align reimbursement, policies, and infrastructure with the unique care pathways involving digital health solutions to increase their uptake [12,13].

Innovation in digital health is largely driven by SMEs, which include businesses with fewer than 500 employees. SMEs develop digital technologies to solve clinical and administrative problems, with a view of selling them to health organizations,

public and private health system payers, and directly to consumers in Canada and internationally. SMEs face unique challenges compared with larger companies in the field because of their lack of connections and leverage in the system and limited resources and access to data to test and develop their solutions. To overcome these barriers, SMEs must develop an efficient clinical model (to promote provider buy-in and value) [14], a strong business model (to promote financial sustainability) [15], and a reliable method to generate evidence (to promote adoption of safe, effective, and valuable technologies of interest to a public payer) [16]. Insights from real-world SMEs attempting to create sustainable and scalable enterprises within the constraints of a public system (rather than research-generated technologies) are critical to creating more symbiotic partnerships between the public system and private industry.

Funding and Regulating Digital Health Technologies in Canada

Funding in the Canadian health system is largely determined by the Canadian Constitution, which allocates responsibility for health care delivery to the provinces. The *Canada Health Act (CHA)* guides funding allocation to provinces for health care delivery, which is collected through a federal tax [17]. The system provides a broad range of health services, divided into 3 layers: those entirely publicly funded (eg, hospitals, physicians, diagnostics), those funded through mixed public and private insurance (eg, prescription drugs, home care, mental health care), and those funded entirely through private insurance (eg, private physiotherapy, dentistry) [18]. There is some variation between provinces in services reimbursed through public insurance: the *CHA* requires that provinces cover services that are *medically necessary*; however, it is left to the provinces to interpret which services fall under this definition. Generally, services provided by a physician are considered *medically necessary*. Private insurance, often provided through employers, fills gaps in health services not covered through public insurance.

There are no regulatory requirements that cover all digital health technologies in Canada. Those meeting the definition of *medical devices*, generally those that are used for diagnosis and treatment, must be specifically approved through Health Canada; however, precise rules and guidelines are often challenging to apply [19]. Health Canada is currently exploring regulatory processes for artificial intelligence–based software that supports clinical decision making [20], which may look similar to the United States Food and Drug Administration's precertification program for digital health. However, many of the tools created by SMEs are either not medical devices or are lower class medical devices that do not require much oversight. This reality leaves hospitals and clinics that wish to adopt digital technologies liable for their safety, efficacy, and security—before any evaluation that has proven such safety and efficacy, as all other institutions are in the same situation. This paper analyzes a series of case studies to identify current health system barriers faced by SMEs developing digital health technologies in Canada and proposes solutions to encourage a more innovative ecosystem.

Methods

The Market Entry Consulting Program

This paper reports on a retrospective evaluation of a real-world program, not a prospective research study with targeted recruitment strategies and protocols geared toward answering a specific question. The reports that were reviewed and qualitatively assessed to produce the content of this study were consolidated by experts in health policy and digital technology, not researchers. The Women's College Hospital Institute for Health System Solutions and Virtual Care (WIHV) established a consultation process for SMEs to help them increase their innovation capacity and take their ideas to market, with support from the National Research Council Industrial Research Assistance Program. WIHV provided market entry consulting

services to SMEs in the digital technology sector in the form of a structured assessment. The process engaged an advisory committee comprising expert advisors in key content domains (informatics, engineering, policy, funding models, and business) alongside health care providers (predominantly physicians but occasionally nurses, pharmacists, and allied health professionals) with relevant clinical expertise. Each SME had between 5 and 8 advisors review its product and business model, which varied depending on the area of practice and availability of the advisors. The advisors reviewed the SME's business model and its product based on the features of the technology itself, the feasibility of its implementation in relevant clinical environments, the potential impact on patients and health systems, and the potential for scale and spread (Table 1). The program was promoted through WIHV's existing network and through scientific conferences and digital technology events.

Table 1. Considerations to guide the evaluation of the small- and medium-sized enterprise product, clinical model, and business model.

Domain	Sample considerations
Technology	
Idea	Mechanism, earlier evidence or validation, innovativeness, and problem definition
Regulatory requirements	Safety and privacy mitigations
Feasibility	
Clinician	Workflow requirements, integration, and behavioral changes
Patient	Required engagement and education
Institutions	Cost, training, human resource requirements, and risk
Health systems	Cost, policy requirements, and risk
Impact	
Patient	Health outcomes, experience, and quality of care
Health systems	Cost-effectiveness and population health impact
Scale and spread	
Political and economic alignment	General interest or need for a product and stakeholder alignment
Innovator	Commitment, experience, skills, and goals
Procurement strategy	Marketing and potential revenue

The consultation process began when an SME completed an onboarding form that provided the advisors with details on their product, marketing strategy, perceived benefit and burden on the health system, expertise, customers, end users, and privacy and security considerations (Multimedia Appendix 1). SMEs identified barriers they had faced in introducing their product to the health system that they wanted the advisors to address. The onboarding form was refined from its initial iteration to efficiently extract relevant information from clients to inform the analysis. SMEs were required to answer all questions. All advisors then independently reviewed the SME's responses following a list of prompts (Table 1). The onboarding and assessment framework for the market entry consulting program was developed using an iterative, co-design approach with stakeholders and experts from multiple disciplines (including medicine, business, technology, health services, and innovation) to capture a broad range of factors important to the success of digital health companies. It was refined based on the experiences and recommendations of the advisors throughout the program.

On the basis of the information provided by SMEs in the onboarding form (including information about the clinical and business models and any explicit challenges noted), the advisors identified system barriers that would make entry into the health system challenging. Each member provided insights and recommendations relative to their expertise to support the SME in navigating the complexities of the health system. Depending on the clinical area of the technology developed by the SME, a content expert (eg, a pharmacist) may be engaged in the review. Insights, barriers, and recommendations were then consolidated to produce a single report that outlines key formative recommendations for the SMEs, which was reviewed by the advisors for accuracy and final comment. A draft of the report was then shared with the SME, after which a debrief meeting was held with all parties to review and refine recommendations. The report was then revised based on discussion, and the final report was sent to the SME (Textbox 1).

Textbox 1. Steps in the market entry consulting process.

The market entry consulting program reported on in this paper involves a multi-step engagement process with small- and medium-sized enterprises (SMEs), as outlined here:

1. Women's College Hospital Institute for Health System Solutions and Virtual Care (WIHV) had the initial contact with SME.
2. The SME provided the completed onboarding form.
3. Committee members reviewed the SME onboarding form.
4. Committee members provided insights and recommendations.
5. WIHV consolidated recommendations into a draft report.
6. The committee reviewed the draft report.
7. The committee met with the SME to review recommendations and insights.
8. WIHV revised the report and provided it to the client.

Ethics

This initiative was formally reviewed and approved by the Chair of the Research Ethics Board for program evaluation projects at Women's College Hospital (Research Ethics Board #2017-0127-E).

Data Collection and Analysis

Data included onboarding forms and final recommendation reports produced for companies assessed by the program from 2016 to 2018. SME data were extracted from the onboarding form to describe the SMEs' characteristics, including the clinical area where a tool would be implemented (eg, cardiology, wound care), primary function (classified according to the National Health Service Evaluation Framework [21], eg, active monitoring), description of the tool and service, intended users (eg, patients, physicians), intended payers (eg, hospitals, physicians), payment model (eg, pay per use), data collected by the tool/service (eg, Personal Health Information), data source (eg, wearable, patient reported), and studies conducted (ie, self-study and/or external evaluation).

We conducted an inductive thematic analysis across all SME reports to identify common health system barriers experienced by SMEs in a digital health innovation who completed the market entry consulting program, as described in the reports produced by the market entry consulting program advisors. Two

members of the research team (JF and KL) independently coded the first 3 reports using NVivo version 11 (QSR International). JF and KL met with a third member of the research team (LK) to review the initial codes and resolve discrepancies to develop a preliminary coding structure. JF and KL then applied and expanded upon the resulting coding structure in the remaining reports. Data were stored and organized into emergent themes in NVivo. Final themes were identified through team discussion to identify the overarching, pervasive barriers to digital technology innovation faced by several innovators.

Results

Characteristics of SME Products

Data from 25 SMEs were reviewed. Table 2 provides an overview of companies' functions, users, payment model, data collected, and evaluations conducted. A total of 11 technologies developed by the participant SMEs coordinated or optimized administrative functions in public or private health institutions (eg, a tool to improve patient transitions). Moreover, 7 technologies actively monitored chronic conditions by collecting and sending patient-generated data to health care providers for review either in real time or intermittently. The remaining 7 technologies had a variety of purposes, including disease self-management, advanced diagnostics, or clinical decision support.

Table 2. Characteristics of small- and medium-sized enterprises' clinical model, business model, and their digital health tools as extracted from the onboarding forms completed by the small- and medium-sized enterprises, sorted by Clinical area.

Clinical area and primary function	Description of the technology/service	Intended users	Intended payers	Payment model	Data collected by the tool/service	Data source	Studies conducted
Geriatrics, cardiology, and respirology							
Active monitoring							
SME ^a 1	Active monitoring of vitals for high-risk patients	Patients, physicians, and pharmacists	Patients, public institutions (hospitals and clinics), and physicians	Pay per use	Collects PHI ^b	Wearable	Self-study
Cardiology							
Active monitoring							
SME 2	Active monitoring of vitals for high-risk patients	Patients	Public institutions (hospitals and specialist clinics) and private insurance	One-time purchase, rental fee per user	Collects PHI	Wearable	External evaluation and self-study
Cardiology and respirology							
Active monitoring							
SME 3	Active monitoring of vitals for high-risk patients	Physicians, patients, and researchers	Public institutions (hospitals and clinics), private insurance, and contract research organizations	One-time purchase	Collects PHI	Wearable	External evaluation and self-study
Dermatology							
Active monitoring							
SME 4	Active monitoring of dermatology	Physicians and nurses	Public institutions (hospitals and clinics) and public/private institutions (home care)	Subscription fee per user	Collects PHI	Images taken by provider	Self-study
SME 5	Active monitoring of dermatology	Physicians and nurses	Public institutions (hospitals and clinics) and public/private institutions (home care)	One-time purchase, subscription fee	Collects PHI	Images taken by patient	External evaluation and self-study
SME 6	Active monitoring of dermatology	Patients and health care providers	Public/private institutions	One-time purchase, subscription fee	Collects PHI	Patient reported	External evaluation and self-study
Mental health							
Active monitoring							
SME 7	Active monitoring of mental health treatment	Therapists and patients	Public institutions (hospitals and primary care clinics), private health institutions (psychotherapy clinics), and private insurance	Subscription fee per user	Collects PHI	Patient reported	Self-study
System services							
SME 23	Coordination of web-based therapy appointments	Patients	Patients and private insurance	Pay per use	Collects PHI	Patient reported	Self-study
Chronic disease							
Self-manage							

Clinical area and primary function	Description of the technology/service	Intended users	Intended payers	Payment model	Data collected by the tool/service	Data source	Studies conducted
SME 8	Self-management of chronic disease	Patients and researchers	Private insurance and contract research organizations	Subscription fee per user	Collects PHI	Patient reported	External evaluation and self-study
SME 9	Self-management of chronic disease	Patients	Patients	Subscription fee	Collects PHI	Wearable	External evaluation and self-study
SME 10	Monitoring and managing chronic disease using wearables	Patients	Patients and private insurance	Subscription fee per user	Collects PHI	Wearable	External evaluation and self-study
Diagnose							
SME 12	Diagnosis and monitoring of chronic disease	Physicians, nurses, caregivers, and research teams	Patients	Subscription fee per user	Collects PHI	Patient reported	Self-study
Nonspecific							
Calculate							
SME 11	Artificial intelligence-based insights into disease patterns	Physicians, nurses, and research teams	Private insurance and contract research organizations	Subscription fee per user	No PHI, de-identified data	Large clinical data sets	Self-study
System services							
SME 17	Administrative and clinical workflow optimization	Health care providers and administrators	Public institutions (hospitals and chronic disease agencies) and private insurance	Subscription fee	Collects PHI	EMR ^c	External evaluation and self-study
SME 18	Administrative optimization of clinics	Administrators and patients	Private institutions (pharmacies) and public institutions (primary care clinics)	Revenue-share model	Transmits PHI (does not store or collect)	Patient reported	Self-study
SME 24	Capture previsit patient information/send information to optimize clinical workflow	Patients, health care providers, and administrators	Other vendors (white label) and public institutions (hospitals and clinics)	Pay per use	Collects PHI	EMR	Self-study
SME 25	Capture previsit patient information/send information to optimize clinical workflow	Patients, physicians, and administrators	Public institutions (hospitals and clinics)	Subscription fee per user	Collects PHI, patient experience survey	EMR, patient reported	External research and self-study
Acute disease							
Diagnose							
SME 13	Diagnosis of certain acute diseases	Patients	Patients and private insurance	One-time purchase	No PHI	N/A ^d	External evaluation
Postacute care							
Inform							
SME 14	Postacute care discharge planning	Patients and caregivers	Public/private institutions (home care) and public institutions (hospitals)	Pay per use	No PHI, patient surveys	Patient reported	Self-study
Pharmacy							

Clinical area and primary function	Description of the technology/service	Intended users	Intended payers	Payment model	Data collected by the tool/service	Data source	Studies conducted
System services							
SME 15	Medication management and renewal	Pharmacists, physicians, and patients	Private institutions (pharmacies) and private insurance	Pay per use	Collects PHI	EMR	Self-study
SME 16	Medication management, renewal, and symptom tracking	Patients and pharmacists	Private institutions (pharmacies)	Setup fee, subscription fee, pay per use	Views PHI (does not store or collect)	Local pharmacy server	Self-study
Primary care							
System services							
SME 19	Administrative optimization of clinics	Administrators, physicians, and patients	Public institutions (primary care clinics and specialist clinics) and private institutions (health and wellness)	Rental fee	Collects PHI	Patient reported	Self-study
SME 20	Coordination of home visits	Patients, physicians, and caregivers	Physicians	Subscription fee, pay per use	Collects PHI	Patient reported	Self-study
Home care							
System services							
SME 21	Coordination of home care services	Patients and caregivers and personal support workers	Private institutions (home care)	Pay per use	Collects and transmits PHI	Patient reported	Self-study
Physiotherapy							
System services							
SME 22	Coordination of home visits	Patients	Patients and private insurance	Pay per use	Collects PHI	Patient reported	Self-study

^aSME: small- and medium-sized enterprise.

^bPHI: personal health information.

^cEMR: electronic medical record.

^dN/A: not applicable.

Two central themes were identified, each with 3 subthemes. First, a common barrier to system integration was the lack of formal evaluation, with SMEs having limited resources and opportunities to conduct such an evaluation. Second, the health system's current structure does not create incentives for clinicians to use digital technologies, which threatens the sustainability of the SMEs' business models.

Lack of Access to Evaluation Resources Was a Barrier to Implementing Digital Technology in Clinical Settings

Digital technology SMEs lack access to clinical evaluations. This leads to uncertainty in the value these tools provide, which makes procurement by third parties highly challenging.

Lacking Evidence of Value

The advisors articulated several concerns regarding the lack of evidence on the value of the technology and lack of clarity on the issues that the technology sought to address. Fewer than half of the companies had conducted an external evaluation (Table 2). The advisors linked the absence of evidence on the

effectiveness and value of downstream challenges with procurement and uptake. The advisors proposed that SMEs invest in generating robust clinical and economic evidence to substantiate claims—an important prerequisite for payers, providers, and other health care purchasers to identify the most impactful digital health products and services:

Generally, public sector payers [...] will be looking for clear evidence that a solution moves metrics along each side of what is known as the Triple Aim—improved health outcomes, improved experience of care, greater value (lower cost). [Excerpt from the SME 24 report]

The advisors encouraged SMEs to identify meaningful metrics in early discussions with potential procurers to ensure alignment of evidence generated with information that supports procurement decisions. Evaluating a tool in a clinical environment provides evidence of value to clinicians, whose engagement is required to adopt the technology. The advisors cautioned that this evidence had to be curated from a trusted source with high methodological quality to ensure credibility:

The clinicians will immediately want to know the answers to the following before considering use of the device, and will want evidence to back up the answers: a. Is this device of equivalent diagnostic fidelity to other devices? b. Does having this information get me through my clinic more effectively? c. Does having this information allow me to make better decisions? d. Does this data, whether provided to clinician or patient, improve on a significant health outcome? [Excerpt from the SME 3 report]

Methods for Generating Evidence

Recommended methods of evidence generation were often contingent on an SME's stage of maturity and reach in the market. An SME's decision not to conduct an external evaluation was typically related to a lack of funding and perceptions by SMEs that it was not a necessary precursor of market entry for their tool. The advisors frequently recommended that SMEs engage in small-scale external evaluations (ie, shorter duration and less cost) to meet system needs, including evidence of acceptability, usability, demand, integration, and implementation. SMEs at earlier stages of development were advised to run smaller pilot studies to refine the technology and business model as a prerequisite for scale to ensure user and payer value propositions were established:

[C]onduct a small-scale evaluation of [product] in an idealized population of practitioners and patients informed by the Triple Aim. A large-scale, multi-center evaluation will be costly and high risk of failure without smaller scale refinement. Ideally, this evaluation would occur with an experienced evaluation partner and the university setting may be ideal. [Excerpt from the SME 23 report]

For more mature SMEs with existing, objective evidence of value, the advisors suggested a more comprehensive assessment of impact across the Institute for Health Improvement's Triple Aim framework using a randomized control or pragmatic trial design. This was seen as a necessary step to establish external validity and generalizability, particularly before implementation within different contextual environments:

We recommend then running a trial to link your tool to outcomes for clinicians, patients, and the system (e.g. faster time to healing, reduced severity of wounds, reduction of complications, reduced cost, etc.). [Excerpt from the SME 5 report]

Challenges in Executing Evaluations

It was widely acknowledged that the need for rapid advancement, evaluation, and distribution of digital health technologies was in direct conflict with the complex and conservative nature of health care research. Generating high-quality clinical evidence is expensive, cumbersome, and time consuming because of the administrative and regulatory requirements imposed by health systems for testing in real-world clinical environments. This challenge is further exacerbated by the fact that measuring outcomes postmarket entry (eg, impact on patient health outcomes and health system costs) often

requires high-resource, large-scale studies. For certain SMEs, generating evidence was further derailed because their service was designed to address factors upstream of patient care (eg, health promotion or educational initiatives), making direct measurement of their impact difficult:

Determine your impact on health institutions and systems: Before you move into the clinical space, it is important to understand the value proposition brought forth by [product]. The place where this application will offer value (e.g. in system cost-savings, improved patient care, in the patient's home) will determine who to target as a customer. [Excerpt from the SME 12 report]

The advisors provided 2 main solutions to address SME barriers. First, several funding sources, namely, grant opportunities, were identified to highlight opportunities for SMEs to access financial resources to conduct an evaluative study. Second, the advisors suggested strategic partnerships with clinical organizations and health system experts who could help them navigate the complex clinical and institutional requirements to run a high-quality evaluation and to access clinical environments to run a trial:

Forging relationships is critical to your success. It is important that you [...] have dedicated resources in this task. Also recognize that international experience is nice, but what you truly need is experience working with the depth and breadth of entities in the Canadian context if you are to be successful in Canada. [Excerpt from the SME 18 report]

The Sustainability of Business Models Was Often Threatened by Inefficiencies in the Current System Structures, Which Minimize Incentives to Use Digital Technologies

System-level incentives for care provisions are outdated and discourage clinicians from adopting digital technology and misalign drivers of institutional procurement and user adoption. The 3 primary structural barriers repeatedly identified throughout the reports were the lack of (1) physician incentives for use of digital technologies, (2) public funding for hospitals and clinics to use digital tools, and (3) incentives to use digital tools for care coordination.

Creating Incentives for Physicians as Users

The viability of clinicians as primary users of a technology is often highly contingent on, or at times in conflict with, their prevailing funding model. For example, in Ontario, during this study, when physicians engaged with a patient virtually *in lieu of* seeing a patient in-person, there was a significant reduction in revenue for similar, or at times greater, clinical effort (eg with tools whose clinical case is predicated on real-time data monitoring). There is no remuneration model for data monitoring outside the boundaries of an office visit, which is at odds with the use case proposed by some SMEs:

Consider the clinical integration. If [product] is integrated in the ways the business plan suggests (i.e. as a "billable" / "prescribe-able" [product] in the Canadian context), there will need to be real

consideration of the existing clinical workflows; and how [product] will fit into them. This becomes most important for integration for whichever clinical care provider acts as the “recipient” of data or notifications from the platform. This is further complicated when considering multiple disease specific platforms for management. Recognize that, unfortunately, financial incentives are not available to clinicians to manage this type of data—many who would be receiving them are fee for service. [Excerpt from the SME 10 report]

The advisors recommended that SMEs could address this by better understanding the funding models in which their technologies fit and attempting to construct business cases around them. For example, in a fee-for-service system, there is value in a technology that increases throughput relative to the necessary increase in effort. In the case of SME 6, the proposed technology enables patients to monitor their wound healing at home and improve clinical triage by leveraging smartphones to take images over time. Reviewing these data with the patient has the potential to reduce the amount of time required for in-person appointments by allowing a rapid review of images. This is in contrast to the current standard of obtaining a complex history using subjective wound and skin descriptors that are challenging for patients to understand. Relatedly, the advisors recommended that SMEs leave physicians out of the equation, as involving busy clinicians unnecessarily creates obstacles to the business case. Involving physicians often involves significant behavioral and clinical workflow changes, which can be difficult to convince them to do without dedicated funding:

The current workflow needs to consider change in practice. If a clinician administers surveys, it is often through paper and pencil. The use of digital technology could improve this. However, a significant barrier to scale is that most clinicians do not use ongoing monitoring in their practice and would require significant behaviour change and clinical education. [Excerpt from the SME 7 report]

Public Versus Private Payers

Most SMEs proposed several potential payers for their technology, which makes it difficult to establish a sustainable business model. There were common challenges in identifying value propositions for publicly funded hospitals and clinics to procure digital technologies because hospitals are funded through the provision of in-person services:

Selling to hospitals is an unlikely market: The value proposition for healthcare institutions such as hospitals is unclear, as there is no reimbursement for real time remote monitoring (only retrospective). Further, you would have to go through burdensome procurement processes to be used. [Excerpt from the SME 2 report]

Many SMEs proposed that the value-add for organizations was reducing the number of clinical visits. However, innovators failed to recognize that system benefits (eg, overall reduction in system use because of improved patient outcomes) are not often reflected at the institutional level. Institutions have

minimal incentive to procure a technology that fixes on a system issue but takes away from their own business and revenue:

Market can be challenging in that there are system-level incentives but health institutions see minimal benefit: There may be difficulty in obtaining buy-in since benefits/cost savings accrue at the system-level, but the institutions could actually lose money if, for example, this were used to reduce the number of visits by a homecare agency or to a wound care clinic. [Excerpt from the SME 5 report]

The advisors frequently recommended that the SMEs sell to private clinics as an alternative to public payers, as there are more direct incentives to procure technologies that reduce the need for in-person visits or time spent with salaried clinicians:

Consider marketing this to institutions with competitive markets: This could include ancillary services such as physiotherapy, chiropody, chiropractic, ultrasound clinics, etc., that need to attract customers. They could use patient feedback to improve their services and market their satisfaction rates. [Excerpt from the SME 25 report]

Given that direct reimbursement for many digital technologies (such as remote monitoring of patient data) is not available at scale across the system, the advisors recommended that companies consider partnerships with insurance companies or employee assistance plans, whereby digital technologies can help identify and effectively manage *at-risk* groups. In Canada, private insurance companies that are funded primarily through employer benefits programs are increasingly paying for supplemental digital health services such as virtual medical appointments, health tracking tools, and other benefits that reduce missed days at work.

Creating Incentives for Care Coordination Between Fragmented Systems

Most technologies boasted the functionality of collecting and storing personal health information, which led SMEs to construct a value proposition around sharing this information across clinician groups to improve decision making. Unfortunately, the siloed reality of the health system meant that there were rarely preexisting channels for data and information sharing, undermining the ability for the technology to realize its stated value across institutional boundaries:

In homecare, there are multiple providers involved in the care of patients. It is important to understand how this information can be shared between them and who is responsible for acting upon the information. EMR integration or EMR-compatible files can be valuable in sharing information. [Excerpt from the SME 6 report]

In the absence of preexisting practices for effective data sharing, SMEs are tasked not only with providing the mechanism for sharing this information but also with creating a model that creates incentives for institutions and clinicians to change their behavior to send and receive these data:

Your overview also talks about integrating systems that currently don't integrate (i.e. pharmacies). This is not a technical problem but is largely a bureaucratic and political problem. What role will you play in sorting those issues out (if any)? [Excerpt from the SME 1 report]

Technology interoperability and integration were central issues. Most clinical organizations communicated to SMEs that they wanted everything to integrate into their electronic medical record (EMR) to minimize workflow disruption. However, it becomes highly burdensome for SMEs to seamlessly integrate into EMRs across health institutions because most institutions have distinct, noninteroperable EMRs. As such, SMEs carry the burden of reconfiguring their technology for the unique integration needs of each health institution, creating an obstacle for scalability and broader system transformation.

Discussion

Principal Findings

The 25 case studies presented in this study exemplify the challenges of developing a successful, evidence-informed business model for digital health technologies in publicly funded systems. Consistently, these SMEs faced significant challenges in engaging users and payers from the public system due to perverse economic incentives. Physicians are compensated by in-person visits, which actively works against the goals of many digital health technologies to keep patients out of clinics and hospitals. Many hospital payment models are based on visit volumes, where there are no incentives to invest in technologies that improve patient and system outcomes and, in turn, reduce volumes. Creating de novo fee codes from a government for uncovered virtual care services is complex, bureaucratic, time consuming, and infeasible for an SME to pursue. Further, reluctance from health systems, institutions, and providers to engage with digital health often relates to deficient evidence of clinical value. Funding for the evaluation of such innovations, including resources for proper implementation, which is costly for resource-constrained recipient sites, is lacking in public health systems.

COVID-19 has introduced rapid shifts in funding models and encouraged the adoption of digital technologies due to the high cost of physical contact. However, it is unclear what billing changes will be sustained, and innovative technology is yet to be adopted at scale. Although there is mass adoption of virtual visits, incentives for clinicians in publicly funded systems to use innovative care models such as remote monitoring and clinical decision support remain unclear.

Comparisons With Prior Work

This paper adds to the existing literature by providing a report and analysis of health system barriers faced by real SMEs developing digital health technologies for a publicly funded system. The existing literature consists mostly of policy analysis, wherein academics propose models to improve the evaluation and implementation of digital technologies without case studies of actual SMEs. We could find no comparative literature that assesses existing SMEs' business and clinical models in a public

health system. This paper, therefore, grounds many of the policy findings produced in previous literature in real-world examples.

The barriers identified are not unique to the Canadian health system. Globally, the potential of digital health has scarcely been realized, partly due to SMEs' difficulties in generating rapid and robust evidence to guide investment decisions [3,16,22]. There is tension between industry and health system actors—digital technology evolves rapidly, whereas research is slow and arduous, often taking years to determine that an intervention leads to effective outcomes [3,23]. Most health professionals seek randomized controlled trials as proof of value [24,25]. However, to minimize the risk of failure, SMEs with less mature technologies would benefit from smaller evaluations to refine their products before engaging in large trials. Due to complex implementation and contextual factors (eg, user experience, engagement, and effectiveness) that affect digital health evaluation, and evaluation timelines that are at odds with the modern ultra-rapid evolution of digital tools, there is a need to reduce our reliance on some traditional approaches to generating evidence, such as randomized controlled trials [26].

Conducting a rigorous evaluation is expensive and time consuming, and public funding for digital health research is minimal compared with funding for biomedical research [23]. Further barriers include acquiring clinical expertise, accessing clinical environments for iterative testing, and navigating complex regulatory and ethical standards [22,26,27]. Although there have been some efforts to standardize approaches to digital health evaluations [16,22,27,28], few jurisdictions have attempted to minimize barriers to evidence generation. One promising avenue to address these barriers is investment in publicly funded programs that support collaborative studies between researchers, health care organizations, and SMEs. For instance, Health Innovation Manchester offers grant opportunities to market-ready SMEs demonstrating strong evidence of improving population health outcomes, which can be used to support further evaluation activities [29]. There are also several programs and accelerators that offer advice to small businesses on navigating health systems to identify a sustainable business model, including the program outlined in this paper [27,29-31]. Academic medical centers have played a role in advancing digital health in the United States with programs to connect innovators to funding, evaluation, clinical expertise, and business development support [23]. In Ontario, some of our client companies were able to benefit from the Health Technologies Fund implemented in 2016, with the goal of increasing investment in, use of, and evaluation of digital tools in practice. This grant provided dedicated funding for clinical organizations, SMEs, and researchers to implement and evaluate digital health tools in clinical settings. However, it was ultimately canceled [32].

All SMEs who went through the consulting program self-reported having identified issues in the health system themselves and then having developed digital technologies to solve those problems. Many SMEs consulted health system partners (primarily clinicians) in developing their technologies; however, some developed their technologies in isolation. Isolated development required SMEs to convince clinicians and organizations to procure and use their technologies *off the shelf*,

which required significantly more effort to achieve clinical buy-in. One method to address the incentive barrier would be for health organizations to identify problems and to match SMEs to collaboratively solve those problems alongside end users. This would ensure that health organizations and providers are encouraged to use the technology [33]. However, funding to support implementation and sustained use remains a barrier, and scalability can be a challenge if technologies are so locally tailored that they are not generalizable within a broader context.

Limitations

As this paper reports on a real-world consulting program, the results are more limited than those of a typical research study. We were limited by the fact that the information provided by the SMEs and the analysis conducted by the advisors was based on a single interaction that spanned approximately 1 month. As such, we did not have longitudinal data on the challenges faced by the SMEs and the future success of the companies after their engagement with the program. Further, data on barriers were not retrieved by directed interviews but rather by coding key barriers identified by an expert committee engaged in a pragmatic consulting process with real companies. The barriers reported are those that emerged naturally in the consultations with those SMEs, rather than through a targeted research methodology.

Conclusions

In 2006, Herzlinger [34] wrote about why innovation in health care is so challenging, citing conflicting motivations between stakeholders, lack of funding for development and sustainability, and demanding accountability from technology developers as key barriers. In 2020, these barriers persist. COVID-19 has introduced an unprecedented need to provide care through virtual means. To promote high-quality care remotely, innovative digital technologies will be essential. To encourage their adoption, the system must prioritize evaluation and the creation of incentive models that support uptake or risk ongoing stifling of promising innovations. Specific tensions exist between the economic incentives of clinical organizations and the use of tools that would benefit patients' well-being, ultimately because of a disconnect of the primary beneficiaries of tools and those who pay for and use them. This means that SMEs have a greater opportunity for success, growth, scale, and sustainability in private markets. There is a need in publicly funded health systems for dedicated funding for the evaluation of digital technologies, streamlined pathways to clinical integration, and system entry points through aligned incentives of users and payers to improve patient outcomes.

Conflicts of Interest

None declared.

Multimedia Appendix 1

The Women's College Hospital Institute for Health System Solutions and Virtual Care digital technology project on-boarding form.

[DOCX File, 15 KB - [publichealth_v6i4e20579_app1.docx](#)]

References

1. The Private Sector, Universal Health Coverage and Primary Health Care. World Health Organization. 2018. URL: https://www.who.int/docs/default-source/primary-health-care-conference/private-sector.pdf?sfvrsn=36e53c69_2 [accessed 2020-12-02]
2. Micca P, Boozer CC, Shukla M. How Are Investors Positioning for the Future of Health? Deloitte Center for Health Solutions. 2020 Mar 12. URL: <https://www2.deloitte.com/us/en/insights/industry/health-care/health-tech-investment-trends.html> [accessed 2020-12-03]
3. Jain SH. The health care innovation bubble. *Healthc (Amst)* 2017 Dec;5(4):231-232. [doi: [10.1016/j.hjdsi.2017.08.002](https://doi.org/10.1016/j.hjdsi.2017.08.002)] [Medline: [28890260](https://pubmed.ncbi.nlm.nih.gov/28890260/)]
4. Miraldo M, Hauck K, Vernet A, Wheelock A. Variations in the adoption of healthcare innovation: a literature review. In: *Oxford Research Encyclopedia of Economics and Finance*. Oxford, UK: Oxford University Press; 2019.
5. Desveaux L, Shaw J, Wallace R, Bhattacharyya O, Bhatia RS, Jamieson T. Examining tensions that affect the evaluation of technology in health care: considerations for system decision makers from the perspective of industry and evaluators. *JMIR Med Inform* 2017 Dec 8;5(4):e50 [FREE Full text] [doi: [10.2196/medinform.8207](https://doi.org/10.2196/medinform.8207)] [Medline: [29222075](https://pubmed.ncbi.nlm.nih.gov/29222075/)]
6. Shaw J, Agarwal P, Desveaux L, Palma D, Stamenova V, Jamieson T, et al. Beyond 'implementation': digital health innovation and service design. *NPJ Digit Med* 2018;1:48 [FREE Full text] [doi: [10.1038/s41746-018-0059-8](https://doi.org/10.1038/s41746-018-0059-8)] [Medline: [31304327](https://pubmed.ncbi.nlm.nih.gov/31304327/)]
7. Hwang J, Christensen CM. Disruptive innovation in health care delivery: a framework for business-model innovation. *Health Aff (Millwood)* 2008;27(5):1329-1335. [doi: [10.1377/hlthaff.27.5.1329](https://doi.org/10.1377/hlthaff.27.5.1329)] [Medline: [18780919](https://pubmed.ncbi.nlm.nih.gov/18780919/)]
8. Sittig DF, Singh H. A new sociotechnical model for studying health information technology in complex adaptive healthcare systems. *Qual Saf Health Care* 2010 Oct;19(Suppl 3):i68-i74 [FREE Full text] [doi: [10.1136/qshc.2010.042085](https://doi.org/10.1136/qshc.2010.042085)] [Medline: [20959322](https://pubmed.ncbi.nlm.nih.gov/20959322/)]

9. Vinck I, de Laet C, Stroobandt S, Van Brabandt H. Legal and organizational aspects of remote cardiac monitoring: the example of implantable cardioverter defibrillators. *Europace* 2012 Sep;14(9):1230-1235. [doi: [10.1093/europace/eus004](https://doi.org/10.1093/europace/eus004)] [Medline: [22345377](https://pubmed.ncbi.nlm.nih.gov/22345377/)]
10. Burns LR. *The Health Care Value Chain: Producers, Purchasers, and Providers*. San Francisco, USA: Jossey-Bass; 2002.
11. Gawande A. Why Doctors Hate Their Computers. *New Yorker*. 2018 Nov 12. URL: <https://www.newyorker.com/magazine/2018/11/12/why-doctors-hate-their-computers> [accessed 2020-12-03]
12. Weinstein RS, Lopez AM, Joseph BA, Erps KA, Holcomb M, Barker GP, et al. Telemedicine, telehealth, and mobile health applications that work: opportunities and barriers. *Am J Med* 2014 Mar;127(3):183-187. [doi: [10.1016/j.amjmed.2013.09.032](https://doi.org/10.1016/j.amjmed.2013.09.032)] [Medline: [24384059](https://pubmed.ncbi.nlm.nih.gov/24384059/)]
13. Bhatia RS, Falk W. Modernizing Canada's Healthcare System through the Virtualization of Services. CD Howe Inst E-Brief. 2019. URL: <https://www.cdhowe.org/public-policy-research/modernizing-canada%E2%80%99s-healthcare-system-through-virtualization-services> [accessed 2020-12-07]
14. Jamieson T, Goldfarb A. Clinical considerations when applying machine learning to decision-support tasks versus automation. *BMJ Qual Saf* 2019 Oct;28(10):778-781. [doi: [10.1136/bmjqs-2019-009514](https://doi.org/10.1136/bmjqs-2019-009514)] [Medline: [31147420](https://pubmed.ncbi.nlm.nih.gov/31147420/)]
15. Kimble C. Business models for e-health: evidence from ten case studies. *J Org Excell* 2015 Apr 23;34(4):18-30. [doi: [10.1002/joe.21611](https://doi.org/10.1002/joe.21611)]
16. Labrique A, Vasudevan L, Weiss W, Wilson K. Establishing standards to evaluate the impact of integrating digital health into health systems. *Glob Health Sci Pract* 2018 Oct 10;6(Suppl 1):S5-17 [FREE Full text] [doi: [10.9745/GHSP-D-18-00230](https://doi.org/10.9745/GHSP-D-18-00230)] [Medline: [30305335](https://pubmed.ncbi.nlm.nih.gov/30305335/)]
17. Canada's Health Care System. Health Canada. 2019 Sep. URL: <https://www.canada.ca/en/health-canada/services/health-care-system/reports-publications/health-care-system/canada.html> [accessed 2020-12-03]
18. Martin D, Miller AP, Quesnel-Vallée A, Caron NR, Vissandjée B, Marchildon GP. Canada's universal health-care system: achieving its potential. *Lancet* 2018 Apr 28;391(10131):1718-1735 [FREE Full text] [doi: [10.1016/S0140-6736\(18\)30181-8](https://doi.org/10.1016/S0140-6736(18)30181-8)] [Medline: [29483027](https://pubmed.ncbi.nlm.nih.gov/29483027/)]
19. Jogova M, Shaw J, Jamieson T. The regulatory challenge of mobile health: lessons for Canada. *Healthc Policy* 2019 Feb;14(3):19-28 [FREE Full text] [doi: [10.12927/hcpol.2019.25795](https://doi.org/10.12927/hcpol.2019.25795)] [Medline: [31017863](https://pubmed.ncbi.nlm.nih.gov/31017863/)]
20. Scientific Advisory Committee on Digital Health Technologies (SAC-DHT). Government of Canada. 2018 Jun. URL: <https://www.canada.ca/en/health-canada/services/drugs-health-products/medical-devices/activities/scientific-expert-advisory-committees/digital-health-technologies/terms-reference-2018-05-28.html> [accessed 2020-12-03]
21. Evidence Standards Framework For Digital Health Technologies. National Institute For Health And Care Excellence. 2019. URL: <https://www.nice.org.uk/about/what-we-do/our-programmes/evidence-standards-framework-for-digital-health-technologies> [accessed 2020-12-03]
22. Mathews SC, McShea MJ, Hanley CL, Ravitz A, Labrique AB, Cohen AB. Digital health: a path to validation. *NPJ Digit Med* 2019;2:38 [FREE Full text] [doi: [10.1038/s41746-019-0111-3](https://doi.org/10.1038/s41746-019-0111-3)] [Medline: [31304384](https://pubmed.ncbi.nlm.nih.gov/31304384/)]
23. DePasse JW, Chen CE, Sawyer A, Jethwani K, Sim I. Academic Medical Centers as digital health catalysts. *Healthc (Amst)* 2014 Sep;2(3):173-176. [doi: [10.1016/j.hjdsi.2014.05.006](https://doi.org/10.1016/j.hjdsi.2014.05.006)] [Medline: [26250503](https://pubmed.ncbi.nlm.nih.gov/26250503/)]
24. Zanaboni P, Ngangue P, Mbemba GI, Schopf TR, Bergmo TS, Gagnon M. Methods to evaluate the effects of internet-based digital health interventions for citizens: systematic review of reviews. *J Med Internet Res* 2018 Jun 7;20(6):e10202 [FREE Full text] [doi: [10.2196/10202](https://doi.org/10.2196/10202)] [Medline: [29880470](https://pubmed.ncbi.nlm.nih.gov/29880470/)]
25. Murray E, Hekler EB, Andersson G, Collins LM, Doherty A, Hollis C, et al. Evaluating digital health interventions: key questions and approaches. *Am J Prev Med* 2016 Nov;51(5):843-851 [FREE Full text] [doi: [10.1016/j.amepre.2016.06.008](https://doi.org/10.1016/j.amepre.2016.06.008)] [Medline: [27745684](https://pubmed.ncbi.nlm.nih.gov/27745684/)]
26. Kostkova P. Grand challenges in digital health. *Front Public Health* 2015;3:134 [FREE Full text] [doi: [10.3389/fpubh.2015.00134](https://doi.org/10.3389/fpubh.2015.00134)] [Medline: [26000272](https://pubmed.ncbi.nlm.nih.gov/26000272/)]
27. Marvel FA, Wang J, Martin SS. Digital health innovation: a toolkit to navigate from concept to clinical testing. *JMIR Cardio* 2018 Jan 18;2(1):e2 [FREE Full text] [doi: [10.2196/cardio.7586](https://doi.org/10.2196/cardio.7586)] [Medline: [31758761](https://pubmed.ncbi.nlm.nih.gov/31758761/)]
28. Monitoring and Evaluating Digital Health Interventions: a Practical Guide to Conducting Research and Assessment. World Health Organization. 2016. URL: <https://www.who.int/reproductivehealth/publications/mhealth/digital-health-interventions/en/> [accessed 2020-12-03]
29. Health Innovation Manchester. URL: <https://healthinnovationmanchester.com/> [accessed 2020-12-03]
30. Hochberg YV. Accelerating entrepreneurs and ecosystems: the seed accelerator model. *Innov Pol Econ* 2016 Jan;16:25-51. [doi: [10.1086/684985](https://doi.org/10.1086/684985)]
31. Digital Health London Accelerator. URL: <https://digitalhealth.london/accelerator/> [accessed 2020-12-03]
32. Galang J. Government of Ontario Accepting Applications for \$20 Million Health Technologies Fund. BetaKit. 2016 Jul 6. URL: <https://betakit.com/government-of-ontario-accepting-applications-for-20-million-health-technologies-fund/> [accessed 2019-11-21]
33. Desveaux L, Kelley L, Bhatia R, Jamieson T. Catalyzing digital health innovation in Ontario: the role of an academic medical center. *Healthc Policy* 2020 Nov;16(2):55-68. [doi: [10.12927/hcpol.2020.26353](https://doi.org/10.12927/hcpol.2020.26353)]
34. Herzlinger RE. Why innovation in health care is so hard. *Harv Bus Rev* 2006 May;84(5):58-66, 156. [Medline: [16649698](https://pubmed.ncbi.nlm.nih.gov/16649698/)]

Abbreviations

CHA: Canada Health Act

EMR: electronic medical record

SME: small- and medium-sized enterprise

WIHV: Women's College Hospital Institute for Health System Solutions and Virtual Care

Edited by T Rashid Soron; submitted 22.05.20; peer-reviewed by C Slightam, P Mechael, R Boumans; comments to author 12.06.20; revised version received 22.07.20; accepted 16.09.20; published 10.12.20.

Please cite as:

Kelley LT, Fujioka J, Liang K, Cooper M, Jamieson T, Desveaux L

Barriers to Creating Scalable Business Models for Digital Health Innovation in Public Systems: Qualitative Case Study

JMIR Public Health Surveill 2020;6(4):e20579

URL: <http://publichealth.jmir.org/2020/4/e20579/>

doi: [10.2196/20579](https://doi.org/10.2196/20579)

PMID: [33300882](https://pubmed.ncbi.nlm.nih.gov/33300882/)

©Leah Taylor Kelley, Jamie Fujioka, Kyle Liang, Madeline Cooper, Trevor Jamieson, Laura Desveaux. Originally published in JMIR Public Health and Surveillance (<http://publichealth.jmir.org>), 10.12.2020. This is an open-access article distributed under the terms of the Creative Commons Attribution License (<https://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in JMIR Public Health and Surveillance, is properly cited. The complete bibliographic information, a link to the original publication on <http://publichealth.jmir.org>, as well as this copyright and license information must be included.

Original Paper

An Interactive Text Message Survey as a Novel Assessment for Bedtime Routines in Public Health Research: Observational Study

George Kitsaras¹, BSc, MPH, MSc, PhD, CPsychol; Michaela Goodwin¹, BSc, MPH, MRes, PhD; Julia Allan², MA, MSc, PhD; Michael Kelly³, PhD, FRCP (Hons), FRCPE, FFPH; Iain Pretty¹, BDS, MPH, MSc, PhD, MFDSRCS, FDS, RCS

¹University of Manchester, Manchester, United Kingdom

²University of Aberdeen, Aberdeen, United Kingdom

³University of Cambridge, Cambridge, United Kingdom

Corresponding Author:

George Kitsaras, BSc, MPH, MSc, PhD, CPsychol

University of Manchester

Dental Health Unit

Williams House Manchester Science Park

Manchester, M15 6SE

United Kingdom

Phone: 44 01612261211

Email: georgios.kitsaras@manchester.ac.uk

Abstract

Background: Traditional research approaches, especially questionnaires and paper-based assessments, limit in-depth understanding of the fluid dynamic processes associated with child well-being and development. This includes bedtime routine activities such as toothbrushing and reading a book before bed. The increase in innovative digital technologies alongside greater use and familiarity among the public creates unique opportunities to use these technical developments in research.

Objective: This study aimed to (1) examine the best way of assessing bedtime routines in families and develop an automated, interactive, text message survey assessment delivered directly to participants' mobile phones and (2) test the assessment within a predominately deprived sociodemographic sample to explore retention, uptake, feedback, and effectiveness.

Methods: A public and patient involvement project showed clear preference for interactive text surveys regarding bedtime routines. The developed interactive text survey included questions on bedtime routine activities and was delivered for seven consecutive nights to participating parents' mobile phones. A total of 200 parents participated. Apart from the completion of the text survey, feedback was provided by participants, and data on response, completion, and retention rates were captured.

Results: There was a high retention rate (185/200, 92.5%), and the response rate was high (160/185, 86.5%). In total, 114 participants provided anonymized feedback. Only a small percentage (5/114, 4.4%) of participants reported problems associated with completing the assessment. The majority (99/114, 86.8%) of participants enjoyed their participation in the study, with an average satisfaction score of 4.6 out of 5.

Conclusions: This study demonstrated the potential of deploying SMS text message-based surveys to capture and quantify real-time information on recurrent dynamic processes in public health research. Changes and adaptations based on recommendations are crucial next steps in further exploring the diagnostic and potential intervention properties of text survey and text messaging approaches.

(*JMIR Public Health Surveill* 2020;6(4):e15524) doi:[10.2196/15524](https://doi.org/10.2196/15524)

KEYWORDS

digital technologies; mobile health; child; well-being; development; assessment; bedtime routines; P4 health care; text survey

Introduction

Background

Capturing high quality and quantity of data is the cornerstone of every successful research project. Most research studies, especially those focusing on behavioral, psychosocial, and wider public health research, use traditional approaches including paper-based questionnaires, interviews, and surveys [1]. These techniques can create barriers to participation for specific population groups, while increasing risk to the quality of data (ie, higher rates of drop out and lower response rates) [1-3]. Easier access, higher uptake, and better use of new technologies, especially mobile phones, create the potential of shifting a number of research-related activities away from traditional approaches [1-3]. In recognition of this shift, organizations around the globe, including the US Food and Drug Administration, recommend electronic capture of data for clinical trials, instead of traditional paper-based methods [4]. Moreover, research conducted by pharmaceutical companies, among others, involves considerable use of mobile-based technologies (37%) in clinical trials [1]. Finally, current trends in health care in the era of the rising P4 (predictive, preventive, personalized, and participatory) model demonstrate the need for innovative, cost-effective, and user-oriented approaches [5].

Currently, the use of mobile phones for communication and entertainment is very high, with approximately 93% of the population owning a mobile phone in the United Kingdom [5]. The use of text messages is also high, with an average of 100 text messages sent per mobile phone subscription per month in the United Kingdom [5]. Unlike many other new technologies, people from low socioeconomic backgrounds and varying ethnicities have similar access to mobile technology as the rest of the population [6]. Low income and minority groups not only show similar rates of using mobile phones but also report a higher percentage of text messaging than other groups [5,6]. Additionally, mobile phone use is the highest among less educated adults and those who rent or frequently change their address [7]. Therefore, in research, mobile phone-based text surveys may represent an important tool for accessing, with minimum effort and intrusiveness, a large number of participants, while obtaining high quality and quantity of data from individuals, including those in traditionally “hard to reach” groups.

Assessment of bedtime routines in families with young children represents an area where text surveys may be implemented in order to gain a better understanding of the fluid and dynamic processes involved. Bedtime routines have shown important

associations with a variety of aspects of child development and well-being, especially quality of sleep, dental health, parental psychoemotional well-being, attitude toward learning, and cognitive development [8-15]. Despite evidence highlighting their importance, there is a clear lack of a reliable, flexible, innovative, and user-friendly method of assessment for bedtime routines [16,17].

The main approach when assessing bedtime routines has involved paper-based questionnaires and diaries [18]. Only few studies involved real-life capture of bedtime routines via video recording, possibly owing to the intrusiveness of this method and the associated ethical and legal implications [18]. When using paper-based questionnaires with a retrospective design, the possibility of recall and desirability bias is always present. With routines being incredibly variable and dynamic and with special consideration for intrusiveness and the likelihood of bias, it is important to approach the entire notion of bedtime routine assessment from a different angle. Broader research into families and children has utilized different methodological approaches, such as the ecological momentary assessment, that go some distance in addressing recall bias [19]. However, for most of these approaches, there is a lack of an interactive feature, limiting their dynamic scope.

The proposed novel perspective should use innovative user-friendly technologies that will allow for greater quantity and better quality of data on bedtime routines while minimizing intrusiveness and disruption to participants. Bedtime routines present an area of particular interest for this approach given their dynamic nature that necessitates real-time information collection. If this methodological approach functions in the context of this particular dynamic and repetitive behavior, the same approach can be used in a variety of other research areas.

Objectives

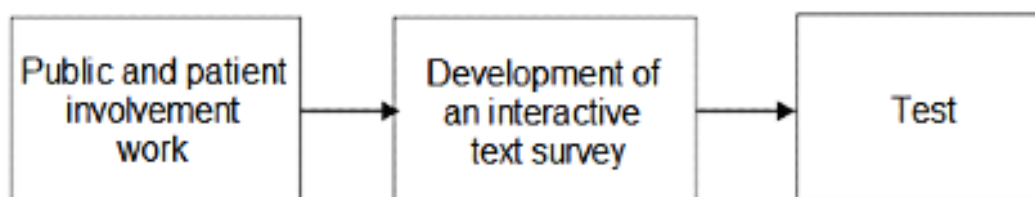
This study aimed to (1) examine the best way of assessing bedtime routines in families and develop an automated, interactive, text message survey assessment delivered directly to participants’ mobile phones and (2) test the assessment within a predominately deprived sociodemographic sample to explore retention, uptake, feedback, and effectiveness.

Methods

Overall Process

The study followed a series of steps, as presented in Figure 1. All steps were necessary since they informed the next stage of the study with important findings mapping back to the two main objectives.

Figure 1. Stepped approach for developing the intervention.



Public and Patient Involvement

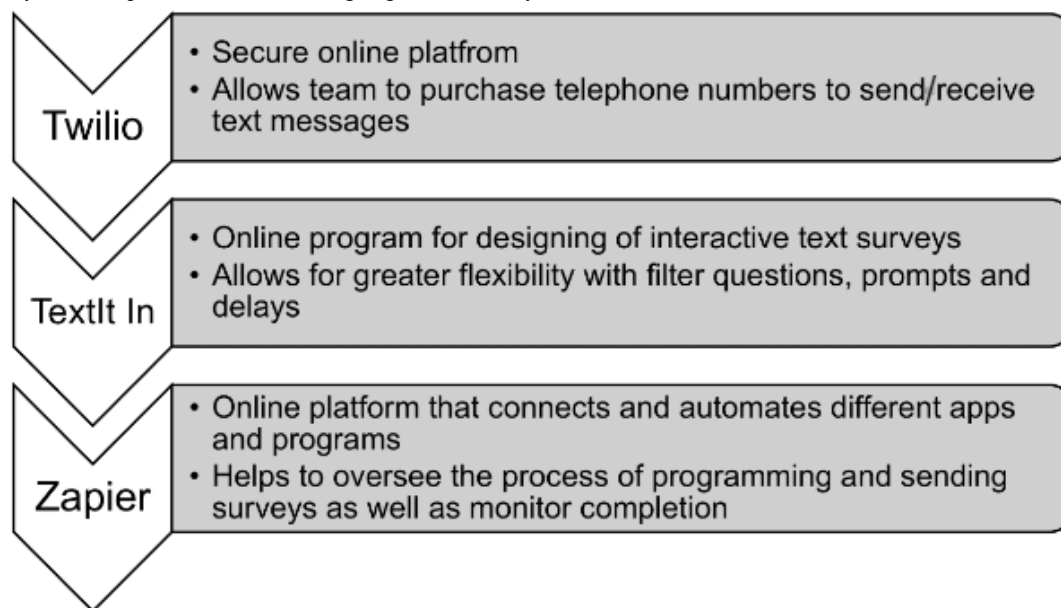
Public and patient involvement (PPI) work, prior to beginning the overall study, was completed during two separate visits to two preschool centers. The targeted sample for the PPI work was parents with children between the ages of 3 and 5 years. During the visits, a total of 15 mothers (no fathers attended the centers during the PPI work) with their children were approached. All mothers approached agreed to take part in the session, and mothers were approached at random. The mothers were asked questions (on a one-to-one basis) about their views on the best way of assessing their children's bedtime routines as a recurrent dynamic health-related behavior. As compensation

for their time, each family received toothpaste and toothbrushes for both adults and children, and a 2-minute toothbrushing timer. [Multimedia Appendix 1](#) presents an overview of the questions and results from the PPI session.

Development of an Interactive Text Survey

Following the completion of the PPI work, an interactive text survey was chosen as the most appropriate method for assessing bedtime routines in families with young children. In total, three readily available software and online platforms were used for the design of the study. [Figure 2](#) presents an overview of how the platforms worked alongside one another to produce the intervention.

Figure 2. Readily available platforms used in redesigning the text-survey.



Using the idea of an ideal bedtime routine, as described by previous studies [18] and expert opinions, the assessment of bedtime routines focused on the following five target areas: (1) consistency (determined as a child going to bed within a space of an hour every night), (2) tooth brushing, (3) snacks/drinks before bed, (4) use of electronic devices before bed, and (5) book reading. These areas have been consistently included in bedtime routine studies as the most important for child well-being and development [18].

Parents predetermined the exact time they would prefer to receive the text survey; however, there was an option to delay the completion of the survey by 30 minutes or 1 hour, or opt out for that night. Detailed instructions on the appropriate answers for each question were provided using examples of accepted answers, and if someone responded incorrectly, a clarification text was sent to them immediately to help them

with their responses. Failure to reply following the instructions in two consecutive attempts led to the end of the survey for that night.

The questions in the interactive text survey were both open-ended and closed. Filter questions (yes/no) led participants to different types of questions. Depending on their replies in filter questions, parents received different responses to strengthen the interactive features of the assessment. Overall, the minimum number of questions to answer each night was eight and the maximum number was 10. All participants were entered into the system via an electronic platform using unique IDs, and all data were managed through secure, university-based, password-protected computers. [Table 1](#) presents a summary of the key characteristics of the interactive text survey as delivered to participants. The overall structure of the interactive text survey is presented in [Multimedia Appendix 2](#).

Table 1. Characteristics of the interactive text survey developed following public and patient involvement work.

Characteristic	Interactive text survey value
Minimum number of questions	8
Maximum number of questions	10
Open questions	Yes
Closed questions	Yes
Question on current parental mood	Yes
Question on self-assessed bedtime routine	Yes
Questions on key bedtime routine activities (eg, tooth brushing)	Yes
Opportunity to delay completion	Yes
Opportunity to opt out on a nightly basis	Yes
Predetermined time to receive assessment	Yes
Number of nights receiving assessment	7
Average completion time (min)	2
Activation of a short code for free-of-charge replies	No

The research team opted out from activating a “short code” that would have allowed participants to reply free of charge. The charge that applied to each reply was made clear to participants at the beginning of the study. The charge per text message reply was dependent upon the mobile phone contract and the provider, with most providers in the United Kingdom providing free unlimited text messages as part of their normal packages [5]. For those who do not have a mobile phone monthly package, a simple text message costs between 1 pence (p) and 10 p per text message depending on the provider [5].

Test Study

Recruitment and Eligibility

Recruitment took place between February and July 2018. Participants were approached during their routine appointments in general dental practices. The exclusion criteria were as follows: (1) not having English proficiency, (2) not owning a mobile phone, and (3) having only children under the age of 3 or over the age of 7 years. Participants were informed about the requirements of the study and asked to provide consent. During recruitment, each participant was informed about the compensation that they would receive at the end of the study in the form of online shopping vouchers. The compensation for their time in the study was a maximum of £10. Early withdrawal affected the amount of compensation.

Sample

In total, 200 parents were recruited. Parents had a mean age of 34.6 years (SD 5.01), with the youngest being 25 years of age and the oldest being 46 years of age. The vast majority of participants were female, with only 12.0% (24/200) male. Most families had only one child (130/200, 65.0%), with 5.0% (10/200) of families having three or more children. All the children were between the ages of 3 and 7 years. In total, 48.0% (96/200) of the sample had a white ethnic background, 39.5% (79/200) had an Asian/British-Asian ethnic background, and 12.5% (25/200) had a Black/Black British/Caribbean ethnic background. The vast majority (156/200, 78.0%) of participants

lived in deprived areas. Deprivation was determined using the index of multiple deprivation (IMD), where higher scores (and quintiles) reflect higher deprivation. For the study, participants had an average IMD score of 41.83 (SD 16.43) and a maximum IMD score of 79.65, which was double the threshold for the fifth IMD quintile.

Data Collection

All participants received the interactive text survey on their mobile phones at a predetermined time for a total of seven consecutive nights. As described above, the assessment focused on their bedtime routine activities with a combination of open and closed questions. Feedback was collected using an automated feedback system utilizing the text survey. This system, like the bedtime routine assessment, included both open and closed questions for the experience of each parent. Finally, data relating to uptake, response, and retention rates were collected through an electronic platform (TextIt).

Data Analysis

All data were transferred and coded in SPSS (IBM SPSS Statistics for Macintosh, Version 25.0) for analysis. Data analyses focused on (1) bedtime routine activities with data collected from the interactive text survey, (2) feedback data regarding user experience, and (3) uptake, retention, and response rate information.

Ethical Approval and Consent to Participate

The study in its entirety, including consent forms and all study materials, was previously approved by the Health Research Authority (Integrated Research Application System [IRAS]; ID: 235385; Tyre and Wear South Committee). All participants accepted anonymized use of their data for further analyses and subsequent publication during consent. Written consent was obtained during recruitment. We obtained consent to publish from the participants (or legal parents or guardians for children) to report individual patient data.

Availability of Data and Materials

The data sets used and/or analyzed in this study are available from the corresponding author on reasonable request.

Results

Uptake, Retention, and Response Rates

Of the 200 participants, 185 completed data collection, resulting in an overall 92.5% retention rate over the 7-day period. A total of 11 participants failed to reply to all of the text surveys, and only four participants opted out of the study after providing replies to at least one night of text surveys using the automated opt-out function.

From the 185 people who completed data collection, there was an average response rate across all nights of 87.0% (161/185).

Table 2. Overview of assessment completion each night.

Night	Completion value (N=185), n (%)
1	176 (95.1%)
2	174 (94.1%)
3	169 (91.4%)
4	164 (88.6%)
5	157 (84.9%)
6	146 (78.9%)
7	138 (74.6%)

Feedback From Users

In total, 114 participants provided anonymized feedback. The majority (99/114, 86.8%) of participants enjoyed their participation in the study, with an average satisfaction score of 4.6 out of 5 and no score below 3 based on the automated feedback system we deployed at the end of the study. The vast majority (107/114, 93.8%) of participants reported high satisfaction scores in receiving and replying to the text messages for seven nights. The average satisfaction score was 4.3 out of 5, and again, no score was below 3. Only a small number (5/114, 4.4%) of participants reported problems caused to their bedtime routines from receiving and replying to the text messages every night for seven nights in total. The low number of people who reported problems may highlight the limited intrusiveness of text messages in assessing behaviors. Participants found the text messages and the questions asked through them to be extremely easy to understand, with an average satisfaction score of 4.9 out of 5. All participants would recommend using text surveys for assessing bedtime routines in future research. The majority (63/114, 55.3%) of those who provided feedback supported the development of a bedtime routine text message support system for those who struggle with their bedtime routines. Finally, a marginal majority (59/114, 51.8%) of participants reported being helped by the nightly text messages in remembering what to do during their bedtime routines.

Effectiveness in Assessing Dynamic Behaviors

During the study, participants replied to a total of 1125 text surveys, generating 9157 unique data points. On average, each

There was a steady decrease in the response rate per night during the study, with the first three nights showing response rates over 90%, while the last two nights of the assessment showed response rates below 80%. This may reflect fatigue with the assessment over time. On average, participants replied to at least 5.5 nights of text surveys. The majority (80/185) of participants replied to six nights, while 62 participants replied to all seven nights, 39 replied to five nights, and four replied to only four nights of the text survey. When participants received the text survey and engaged by replying to it, they completed the full survey. Once a participant started the assessment, he/she continued until the last question, resulting in a 100% completion rate per survey, with no missing data associated with noncompletion. [Table 2](#) provides an overview of the completion of the assessment each night.

participant generated 50 unique data points by replying to an average of nine questions per night during the course of the study. The deployment of the interactive text survey allowed for a more in-depth observation of bedtime routine activities in families with young children. A small majority (95/185, 51.4%) of participants reported brushing their children's teeth every night, while only a small percentage (2/185, 1.1%) reported never brushing teeth before bed. With regard to diet, 57.8% (107/185) of participants reported allowing food and/or drinks the hour before bed at some point during the week. A total of 24.9% (46/185) of participants read to their children every night of the week, 9.2% (17/185) never read or shared a book with their children during the course of the study, and 29.2% (54/185) read or shared a book with their children for at least half of the nights. Finally, with regard to the use of electronic devices the hour before bed, 13.5% (25/185) of parents allowed electronic devices to be used the hour before bed.

Discussion

Principal Findings

Overall, the interactive text survey assessment of a recurrent dynamic behavior provided a large quantity and good quality of data on the targeted behavior. It managed to keep participants engaged throughout the duration of the study with limited drop out. Finally, the interactive text survey created a user-friendly nonintrusive experience for participants, as reflected in their feedback ([Table 3](#)).

Table 3. Key results of the study.

Metric	Value, n (%) or score/number
Retention (N=200)	185 (92.5%)
Response (overall) (N=185)	161 (87.0%)
Overall feedback score (scale 0-5)	4.6
Easiness of use score (scale 0-5)	4.9
Reported problems to routines from receiving the assessment (N=114)	5 (4.4%)
Recommended text surveys for future assessments (N=114)	114 (100%)
Supported development of a text messaging bedtime routine intervention (N=114)	63 (55.3%)
Average unique data points	50

The benefits of administering an interactive text survey assessment for recurrent dynamic behaviors can be divided into the following three areas: (1) limiting recall bias, (2) securing higher volumes of data, and (3) providing a better experience for participants. Recall bias can have a potentially detrimental effect on research findings by either underestimating or overestimating the true effect of a given behavior [20]. Recall bias can be affected by a number of areas, with time elapsing between the targeted behavior and assessment of that behavior being one of the most prominent [21]. In traditional assessments, including questionnaires, with a retrospective approach (in some cases, up to a month after the targeted activity), recall bias has the potential to influence both the quality and quantity of collected data owing to the time lapsed [20]. In recurrent and dynamic behaviors, like bedtime routines, with a fluid nature, a narrow timeframe between the activity and assessment of the activity is crucial to be able to capture and investigate their intricate nature. With the development and utilization of approaches that capitalize on narrow timeframes, recall bias can potentially be eliminated.

As for the second area (securing high volumes of data), the deployment of the text survey assessment for bedtime routines led to a considerably higher response rate than with traditional questionnaires [22]. Additionally, once participants started answering the survey on a given night, they completed it without stopping midway or missing any of the questions. This resulted in an average of 50 unique data points. High response rates in conjunction with multiple data points over a short period of time resulted in wider flexibility when conducting further analyses. Finally, with respect to providing a better experience for participants, across all questions on the feedback form, most participants reported no issues and reported a high satisfaction rate. Moreover, when asked at the end of the study, every participant showed a clear preference for a text survey–style assessment against other measures, including questionnaires and video recordings. Across health-related research and intervention studies, there is considerable variation in retention rates, with some studies reporting retention rates as high as 97% and as low as 56% [23–25]. Approaches, such as interactive text surveys, should be further explored and utilized as an alternative method in achieving better user engagement and retention.

In this study, text surveys were used primarily for data collection as an alternative to traditional questionnaire and paper-based assessments for bedtime routines. As discussed, utilization of

text surveys and text messages is not limited to data collection, with multiple other functionalities from recruitment to interventions [1,25]. Their increasing availability in conjunction with higher use of mobile phones across all age and demographic groups presents a great opportunity for harnessing their wide spectrum of applications in both research and clinical settings. Multiple organizations like the National Health Service (NHS) in the United Kingdom now deploy text messages and text surveys to contact and remind patients of their appointments and/or to gather feedback about services [26]. These examples showcase in practice how mobile phone–based text surveys and text messages can be used in a reciprocally beneficial relationship where service users or participants and organizations are mutually benefited. Solely for clinical applications, today’s demanding, dynamic, and highly variable health care needs present a great opportunity for mobile phone–based text messages given their cost effectiveness, high adaptability, and flexible format [27–29]. This opportunity is also relevant for pediatric populations given their clear preference for tailored, technology-based, and interactive programs such as mobile phone–based text messages and surveys [29].

Finally, medicine and health care as a whole are slowly but steadily moving to a personalized model of care, as shown by the recent P4 model [30,31]. This model emphasizes the importance of transforming the service from a reactive to a proactive one with regard to disease and care [32]. Even though the model is mainly focused on clinical and long-term conditions, including diabetes, cancer, and cardiovascular diseases, the same approach could possibly be used in a variety of health-related, well-being–related, and development-related behaviors. The P4 model of medicine and health care is driven by the evolution, expansion, and merging of the following three megatrends: (1) systems biology/systems medicine, (2) digital technologies for health care, and (3) consumer-driven health care [30]. Therefore, text message–based applications, including text surveys, can be active components in the era of P4 medicine and health care owing to their versatility, low cost per participant, ease of use, high personalization, and adaptation that transcends cultural, linguistic, and demographic boundaries.

Limitations

The utilization of a stepped approach in designing, refining, and redeveloping an interactive text survey helps to minimize its limitations. However, there are several areas where

limitations are evident. One of the most important is with regard to the risk of bias, especially desirability bias. As with every assessment that relies on self-reported data, desirability bias cannot be fully excluded. Moreover, as highlighted by the comments made by several participants, despite attempting to only assess bedtime routines, the text survey might have acted as an unintended intervention, leading to changes in some family routines. This is not necessarily a negative limitation, since this type of feedback allowed for the consideration of intervening properties regarding text surveys and text messaging for bedtime routines. Finally, another limitation to consider concerns the lack of a reference measure for assessing bedtime routines alongside the utilization of the interactive text survey.

Recommendations

Despite the success of the approach, necessary changes and recommendations for future use are vital in further exploring the benefits of text surveys in assessing health-related behaviors. These changes can focus on both further improving user interaction with the system and maintaining an overall good user experience. Specific changes include (1) provision for a number to call when and if issues or difficulties arise during

the completion of the text survey and (2) provision for free-of-charge replies by activating a “short code,” especially for research focusing on deprived socioeconomic areas and populations. Moreover, based on the feedback of some participants and on this particular area of research, it might be important to consider the development and examination of a text message-based bedtime routine intervention for achieving and sustaining better routines for families with young children.

Conclusion

The results of this study showed the potential for deploying text surveys within public health research as an attempt to capture real-time information on dynamic and highly variable recurrent behaviors that can have subsequent implications with regard to development and well-being. It also demonstrated that text surveys can be reliable alternatives for capturing data when compared with traditional methods or other technologies, possibly owing to their nonintrusiveness and generally easier user interface. Overall, text surveys and text messages are emerging as valuable alternative routes for capturing data and delivering interventions in wider public health research.

Acknowledgments

This study is part fulfillment for the requirement of completing a PhD in Dental Public Health at the Dental Health Unit, The University of Manchester. No additional funding was received with regard to the project described in the manuscript. The research team would like to thank all participating families. Moreover, the research team would like to thank all staff members and managers of the participating general dental practices for their unique contribution and support during recruitment.

Authors' Contributions

GK conceptualized and designed the study, organized and completed all recruitment and data collection processes, and wrote and submitted the manuscript. MG, JA, MPK, and IAP contributed to the conceptualization and design of the study, assisted during recruitment and data collection, were actively involved in data coding and analysis in accordance with their research expertise, and were involved in the drafting and critical review of the manuscript while offering invaluable continuous support throughout the process. GK, MG, JA, MPK, and IAP confirm that they have seen and approve the submission of the manuscript. They also state that they are accountable for all aspects of the work presented in the manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Public and patient involvement questions and results.

[[PDF File \(Adobe PDF File\), 158 KB - publichealth_v6i4e15524_app1.pdf](#)]

Multimedia Appendix 2

Branching flowchart for the text survey.

[[PDF File \(Adobe PDF File\), 267 KB - publichealth_v6i4e15524_app2.pdf](#)]

References

1. von Niederhäusern B, Saccilotto R, Schädelin S, Ziesenitz V, Benkert P, Decker M, et al. Validity of mobile electronic data capture in clinical studies: a pilot study in a pediatric population. *BMC Med Res Methodol* 2017 Dec 08;17(1):163 [[FREE Full text](#)] [doi: [10.1186/s12874-017-0438-x](https://doi.org/10.1186/s12874-017-0438-x)] [Medline: [29216831](https://pubmed.ncbi.nlm.nih.gov/29216831/)]
2. Friend SH. App-enabled trial participation: Tectonic shift or tepid rumble? *Sci Transl Med* 2015 Jul 22;7(297):297ed10-297ed10 [[FREE Full text](#)] [doi: [10.1126/scitranslmed.aab1206](https://doi.org/10.1126/scitranslmed.aab1206)] [Medline: [26203077](https://pubmed.ncbi.nlm.nih.gov/26203077/)]

3. Dorsey ER, Venuto C, Venkataraman V, Harris DA, Kiebertz K. Novel methods and technologies for 21st-century clinical trials: a review. *JAMA Neurol* 2015 May 01;72(5):582-588 [FREE Full text] [doi: [10.1001/jamaneurol.2014.4524](https://doi.org/10.1001/jamaneurol.2014.4524)] [Medline: [25730665](https://pubmed.ncbi.nlm.nih.gov/25730665/)]
4. U.S. Department of Health Human Services FDA Center for Drug Evaluation Research, U.S. Department of Health Human Services FDA Center for Biologics Evaluation Research, U.S. Department of Health Human Services FDA Center for Devices Radiological Health. Guidance for industry: patient-reported outcome measures: use in medical product development to support labeling claims: draft guidance. *Health Qual Life Outcomes* 2006 Oct 11;4:79 [FREE Full text] [doi: [10.1186/1477-7525-4-79](https://doi.org/10.1186/1477-7525-4-79)] [Medline: [17034633](https://pubmed.ncbi.nlm.nih.gov/17034633/)]
5. Cape S, Rees J. Communications Market Report. London, UK: Office for Communications; Aug 04, 2016.
6. Militello L, Kelly S, Melnyk B. Systematic review of text-messaging interventions to promote healthy behaviors in pediatric and adolescent populations: implications for clinical practice and research. *Worldviews Evid Based Nurs* 2012 Apr;9(2):66-77. [doi: [10.1111/j.1741-6787.2011.00239.x](https://doi.org/10.1111/j.1741-6787.2011.00239.x)] [Medline: [22268959](https://pubmed.ncbi.nlm.nih.gov/22268959/)]
7. Fjeldsoe BS, Marshall AL, Miller YD. Behavior change interventions delivered by mobile telephone short-message service. *Am J Prev Med* 2009 Feb;36(2):165-173. [doi: [10.1016/j.amepre.2008.09.040](https://doi.org/10.1016/j.amepre.2008.09.040)] [Medline: [19135907](https://pubmed.ncbi.nlm.nih.gov/19135907/)]
8. Davies G, Bridgman C. Improving oral health among schoolchildren - which approach is best? *Br Dent J* 2011 Jan 22;210(2):59-61. [doi: [10.1038/sj.bdj.2011.1](https://doi.org/10.1038/sj.bdj.2011.1)] [Medline: [21252882](https://pubmed.ncbi.nlm.nih.gov/21252882/)]
9. Hale L, Berger LM, LeBourgeois MK, Brooks-Gunn J. Social and Demographic Predictors of Preschoolers Bedtime Routines. *Journal of Developmental & Behavioral Pediatrics* 2009;30(5):394-402. [doi: [10.1097/dbp.0b013e3181ba0e64](https://doi.org/10.1097/dbp.0b013e3181ba0e64)]
10. COUNCIL ON COMMUNICATIONS AND MEDIA. Media Use in School-Aged Children and Adolescents. *Pediatrics* 2016 Nov 21;138(5):e20162592 [FREE Full text] [doi: [10.1542/peds.2016-2592](https://doi.org/10.1542/peds.2016-2592)] [Medline: [27940794](https://pubmed.ncbi.nlm.nih.gov/27940794/)]
11. Kelly Y, Kelly J, Sacker A. Changes in bedtime schedules and behavioral difficulties in 7 year old children. *Pediatrics* 2013 Nov 14;132(5):e1184-e1193. [doi: [10.1542/peds.2013-1906](https://doi.org/10.1542/peds.2013-1906)] [Medline: [24127471](https://pubmed.ncbi.nlm.nih.gov/24127471/)]
12. Levine RS. Caries experience and bedtime consumption of sugar-sweetened food and drinks--a survey of 600 children. *Community Dent Health* 2001 Dec;18(4):228-231. [Medline: [11789700](https://pubmed.ncbi.nlm.nih.gov/11789700/)]
13. Mindell J, Leichman ES, DuMond C, Sadeh A. Sleep and Social-Emotional Development in Infants and Toddlers. *J Clin Child Adolesc Psychol* 2017;46(2):236-246. [doi: [10.1080/15374416.2016.1188701](https://doi.org/10.1080/15374416.2016.1188701)] [Medline: [27492858](https://pubmed.ncbi.nlm.nih.gov/27492858/)]
14. Sadeh A, Tikotzky L, Scher A. Parenting and infant sleep. *Sleep Med Rev* 2010 Apr;14(2):89-96. [doi: [10.1016/j.smrv.2009.05.003](https://doi.org/10.1016/j.smrv.2009.05.003)] [Medline: [19631566](https://pubmed.ncbi.nlm.nih.gov/19631566/)]
15. El-Sheikh M, Sadeh A. I. Sleep and development: introduction to the monograph. *Monogr Soc Res Child Dev* 2015 Mar;80(1):1-14. [doi: [10.1111/mono.12141](https://doi.org/10.1111/mono.12141)] [Medline: [25704732](https://pubmed.ncbi.nlm.nih.gov/25704732/)]
16. Kitsaras G, Goodwin M, Allan J, Kelly MP, Pretty IA. BMC Public Health 2018 Mar 21;18(1):386 [FREE Full text] [doi: [10.1186/s12889-018-5290-3](https://doi.org/10.1186/s12889-018-5290-3)] [Medline: [29562892](https://pubmed.ncbi.nlm.nih.gov/29562892/)]
17. Kitsaras G, Allan J, Pretty IA. Bedtime Routines Intervention for Children (BRIC) using an automated text messaging system for behaviour change: study protocol for an early phase study. *Pilot Feasibility Stud* 2020 Feb 6;6(1):14 [FREE Full text] [doi: [10.1186/s40814-020-0562-y](https://doi.org/10.1186/s40814-020-0562-y)] [Medline: [32047647](https://pubmed.ncbi.nlm.nih.gov/32047647/)]
18. Mindell JA, Williamson AA. Benefits of a bedtime routine in young children: Sleep, development, and beyond. *Sleep Med Rev* 2018 Aug;40:93-108 [FREE Full text] [doi: [10.1016/j.smrv.2017.10.007](https://doi.org/10.1016/j.smrv.2017.10.007)] [Medline: [29195725](https://pubmed.ncbi.nlm.nih.gov/29195725/)]
19. Smyth J, Heron K. Ecological Momentary Assessment (EMA) in Family Research. In: McHale S, Amato P, Booth A, editors. *Emerging Methods in Family Research*. National Symposium on Family Issues, vol 4. Cham: Springer; 2014:145-161.
20. Althubaiti A. Information bias in health research: definition, pitfalls, and adjustment methods. *JMDH* 2016 May;211. [doi: [10.2147/jmdh.s104807](https://doi.org/10.2147/jmdh.s104807)]
21. Kip KE, Cohen F, Cole SR, Wilhelmus KR, Patrick DL, Blair R, et al. Recall bias in a prospective cohort study of acute time-varying exposures. *Journal of Clinical Epidemiology* 2001 May;54(5):482-487. [doi: [10.1016/s0895-4356\(00\)00310-3](https://doi.org/10.1016/s0895-4356(00)00310-3)]
22. Nulty DD. The adequacy of response rates to online and paper surveys: what can be done? *Assessment & Evaluation in Higher Education* 2008 Jun;33(3):301-314. [doi: [10.1080/02602930701293231](https://doi.org/10.1080/02602930701293231)]
23. Zweben A, Fucito LM, O'Malley SS. Effective Strategies for Maintaining Research Participation in Clinical Trials. *Drug Inf J* 2009 Jul 30;43(4):459-467 [FREE Full text] [doi: [10.1177/009286150904300411](https://doi.org/10.1177/009286150904300411)] [Medline: [24311825](https://pubmed.ncbi.nlm.nih.gov/24311825/)]
24. Walters SJ, Bonacho Dos Anjos Henriques-Cadby I, Bortolami O, Flight L, Hind D, Jacques RM, et al. Recruitment and retention of participants in randomised controlled trials: a review of trials funded and published by the United Kingdom Health Technology Assessment Programme. *BMJ Open* 2017 Mar 20;7(3):e015276 [FREE Full text] [doi: [10.1136/bmjopen-2016-015276](https://doi.org/10.1136/bmjopen-2016-015276)] [Medline: [28320800](https://pubmed.ncbi.nlm.nih.gov/28320800/)]
25. Varma DS, Hart M, McIntyre DS, Kwiatkowski E, Cottler LB. A Research Protocol to Test the Effectiveness of Text Messaging and Reminder Calls to Increase Service Use Referrals in a Community Engagement Program. *JMIR Res Protoc* 2016 Jun 28;5(2):e133 [FREE Full text] [doi: [10.2196/resprot.5854](https://doi.org/10.2196/resprot.5854)] [Medline: [27353040](https://pubmed.ncbi.nlm.nih.gov/27353040/)]
26. Douglas J. Accessible Information Standard: Using email and text messages for communicating with patients. National Health Service. 2016 May 01. URL: <https://oxfordaasc.com/view/10.1093/acref/9780195301731.001.0001/acref-9780195301731-e-47561> [accessed 2020-12-15]

27. Gurol-Urganci I, de Jongh T, Vodopivec-Jamsek V, Atun R, Car J. Mobile phone messaging reminders for attendance at healthcare appointments. *Cochrane Database Syst Rev* 2013 Dec 05;7(12):CD007458 [FREE Full text] [doi: [10.1002/14651858.CD007458.pub3](https://doi.org/10.1002/14651858.CD007458.pub3)] [Medline: [24310741](https://pubmed.ncbi.nlm.nih.gov/24310741/)]
28. Leong KC, Chen WS, Leong KW, Mastura I, Mimi O, Sheikh MA, et al. The use of text messaging to improve attendance in primary care: a randomized controlled trial. *Fam Pract* 2006 Dec 11;23(6):699-705. [doi: [10.1093/fampra/cml044](https://doi.org/10.1093/fampra/cml044)] [Medline: [16916871](https://pubmed.ncbi.nlm.nih.gov/16916871/)]
29. Shapiro JR, Bauer S, Hamer RM, Kordy H, Ward D, Bulik CM. Use of text messaging for monitoring sugar-sweetened beverages, physical activity, and screen time in children: a pilot study. *J Nutr Educ Behav* 2008 Nov;40(6):385-391 [FREE Full text] [doi: [10.1016/j.jneb.2007.09.014](https://doi.org/10.1016/j.jneb.2007.09.014)] [Medline: [18984496](https://pubmed.ncbi.nlm.nih.gov/18984496/)]
30. Flores M, Glusman G, Brogaard K, Price ND, Hood L. P4 medicine: how systems medicine will transform the healthcare sector and society. *Per Med* 2013 Aug;10(6):565-576 [FREE Full text] [doi: [10.2217/pme.13.57](https://doi.org/10.2217/pme.13.57)] [Medline: [25342952](https://pubmed.ncbi.nlm.nih.gov/25342952/)]
31. Hood L, Auffray C. Participatory medicine: a driving force for revolutionizing healthcare. *Genome Med* 2013;5(12):110 [FREE Full text] [doi: [10.1186/gm514](https://doi.org/10.1186/gm514)] [Medline: [24360023](https://pubmed.ncbi.nlm.nih.gov/24360023/)]
32. Sagner M, McNeil A, Puska P, Auffray C, Price ND, Hood L, et al. The P4 Health Spectrum - A Predictive, Preventive, Personalized and Participatory Continuum for Promoting Healthspan. *Prog Cardiovasc Dis* 2017 Mar;59(5):506-521. [doi: [10.1016/j.pcad.2016.08.002](https://doi.org/10.1016/j.pcad.2016.08.002)] [Medline: [27546358](https://pubmed.ncbi.nlm.nih.gov/27546358/)]

Abbreviations

IMD: index of multiple deprivation

P4: predictive, preventive, personalized, and participatory

PPI: public and patient involvement

Edited by G Eysenbach; submitted 17.07.19; peer-reviewed by A Herbec, G Siapco, C Lammert, M George; comments to author 11.08.20; revised version received 10.09.20; accepted 27.09.20; published 21.12.20.

Please cite as:

Kitsaras G, Goodwin M, Allan J, Kelly M, Pretty I

An Interactive Text Message Survey as a Novel Assessment for Bedtime Routines in Public Health Research: Observational Study

JMIR Public Health Surveill 2020;6(4):e15524

URL: <http://publichealth.jmir.org/2020/4/e15524/>

doi: [10.2196/15524](https://doi.org/10.2196/15524)

PMID: [33346734](https://pubmed.ncbi.nlm.nih.gov/33346734/)

©George Kitsaras, Michaela Goodwin, Julia Allan, Michael Kelly, Iain Pretty. Originally published in *JMIR Public Health and Surveillance* (<http://publichealth.jmir.org>), 21.12.2020. This is an open-access article distributed under the terms of the Creative Commons Attribution License (<https://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in *JMIR Public Health and Surveillance*, is properly cited. The complete bibliographic information, a link to the original publication on <http://publichealth.jmir.org>, as well as this copyright and license information must be included.

Original Paper

Antivaccine Messages on Facebook: Preliminary Audit

Dhamanpreet Dhaliwal^{1*}, BN; Cynthia Mannion^{1*}, BA, MSN, PhD

University of Calgary, Calgary, AB, Canada

* all authors contributed equally

Corresponding Author:

Cynthia Mannion, BA, MSN, PhD

University of Calgary

2500 University Dr NW

Calgary, AB,

Canada

Phone: 1 403 210 3848

Email: cmannion@ucalgary.ca

Abstract

Background: The World Health Organization lists vaccine hesitancy as one of 10 threats to global health. The antivaccine movement uses Facebook to promote messages on the alleged dangers and consequences of vaccinating, leading to a reluctance to immunize against preventable communicable diseases.

Objective: We would like to know more about the messages these websites are sharing via social media that can influence readers and consumers. What messages is the public receiving on Facebook about immunization? What content (news articles, testimonials, videos, scientific studies) is being promoted?

Methods: We proposed using a social media audit tool and 3 categorical lists to capture information on websites and posts, respectively. The keywords “vaccine,” “vaccine truth,” and “anti-vax” were entered in the Facebook search bar. A Facebook page was examined if it had between 2500 and 150,000 likes. Data about beliefs, calls to action, and testimonials were recorded from posts and listed under the categories Myths, Truths, and Consequences. Website data were entered in a social media audit template.

Results: Users’ posts reflected fear and vaccine hesitancy resulting from the alleged dangers of immunization featured on the website links. Vaccines were blamed for afflictions such as autism, cancer, and infertility. Mothers shared testimonies on alleged consequences their children suffered due to immunization, which have influenced other parents to not vaccinate their children. Users denied the current measles outbreaks in the United States to be true, retaliating against the government in protests for fabricating news.

Conclusions: Some Facebook messages encourage prevailing myths about the safety and consequences of vaccines and likely contribute to parents’ vaccine hesitancy. Deeply concerning is the mistrust social media has the potential to cast upon the relationship between health care providers and the public. A grasp of common misconceptions can help support health care provider practice.

(*JMIR Public Health Surveill* 2020;6(4):e18878) doi:[10.2196/18878](https://doi.org/10.2196/18878)

KEYWORDS

antivaccine; vaccines; vaccination; immunization; communicable disease

Introduction

Many diseases have been almost, or completely, eradicated due to immunization. Immunization against disease prevents 2-3 million deaths per year internationally and could prevent even more with global vaccination improvements [1]. Immunization has vastly decreased mortality due to preventable communicable diseases. For example, before the introduction of the measles vaccine, 300,000-400,000 Canadians were infected every year,

with some recoveries and many deaths [2]. Since the elimination of measles in 1998 due to vaccines, there have been very few cases in Canada [2]. Similarly, once the polio vaccine was introduced in Canada in the 1950s, cases reduced dramatically, and the current risk to the Canadian population is extremely low [3].

The World Health Organization (WHO) has declared vaccine hesitancy as one of the top 10 threats to global health [4]. Social media has helped fuel the growth of the antivaccine movement,

with Facebook being identified as a key disseminator of misinformation surrounding the campaign [5-7]. Facebook is the largest social media platform, with more than 2 billion active monthly users [8]. There have been serious efforts to reduce the amount of misinformation spread on the social media site by lowering the ranking of Groups and Pages making false claims [7]. Social media administrators have been urged to remove these Pages and Groups altogether; however, counterarguments cite a violation of human rights to access uncensored information [7]. This paper exposes the messages of the antivaccine movement online and how individuals perceive immunization. We aimed to uncover the myths and truths that users of Facebook Pages observe and partake in. Health care consumers and health care providers may find themselves on opposite ends of the debate. Lack of immunization places the public at risk and decreases public health efforts to curb measles and polio and prevent outbreaks of influenza (flu) along with other communicable diseases. The shift in power between doctors and patients due to easy access to information online has led to the questioning of health care providers and increased shared decision making [6,9].

As most of the world awaits a vaccine to put an end to the COVID-19 (also known as the 2019 novel coronavirus) pandemic, “followers” of antivaccine Facebook Pages seem to fear the vaccine more than the virus itself [10]. Amid the COVID-19 pandemic, social media sites such as Facebook are unable to control the health misinformation that is spread on its Pages [11]. Antivaccine Pages have been providing conspiracy theories, safety concerns, and alternative health medication that grasp the attention of “undecided” individuals surfing the web for information on vaccines [11]. The WHO is fighting to stop the spread of misinformation online by collaborating with social media giants to find a way to regulate false claims [12]. Some examples of such claims include that COVID-19 is a bioweapon funded by the Bill & Melinda Gates Foundation or that it can simply be cured by consuming homemade concoctions (some include drinking bleach) [13]. Our aim was to know more about the messages that can influence readers and consumers that these websites are sharing via social media.

Methods

Publicly available content on 4 Facebook Pages was analyzed based on the number of likes they received. Keywords “anti-vax,” “anti-vaccine,” “vaccine,” “vaccine injury,” and “stop vaccination” were entered into the Facebook search bar. Once on the “results” page, we followed the link to the “Pages” tab. Pages were chosen if they had between 2500 and 150,000 likes — a measure of the spread of readership. This range was selected based on the fact that it included most pages that had high traffic with daily activity. The Page was selected if it had the highest amount of likes on the first “results” page. We then scrolled down to January 1, 2019 and analyzed posts, comments on posts, and website links shared until May 30, 2019. Flu activity peaks between December and February and can last as late as May [14]. Website and posts data simultaneously reached saturation, the point where no new themes emerged. Website links shared on the Facebook Pages were publicly accessible and consisted of news articles, blog posts, scientific studies, or

website posts of renowned antivaccine activists. The data collected from the Facebook posts were categorized into “Myths,” “Truths,” and “Consequences.” These lists helped categorize the data found on the Facebook Pages to determine the exaggeration of myths and falsehoods and the minimization of truths. A separate category, “Measles Outbreak Reactions,” was used to document reactions to outbreaks of measles happening around the United States that were garnering attention in mainstream media and on the Facebook Pages.

Website data captured from links shared between January 2019 and May 2019 were entered into the Who, What, When, and Why categories of the social media audit template. Using this tool, we were able to capture and categorize data in a uniform manner for all websites. The social media audit template was created by Keith Quesenberry [15]. He describes a social media audit as “a systematic examination of social media data” [15]. We adapted and modified this tool to help us gain insight on what points and messages website authors are trying to get across. This tool is to be used to systemically examine “social talk of a brand” — in this case, the “brand” is the topic of immunization [16] — and allows the examiner to shift their viewpoint from “control” to “engagement” and understand why users are participating in such forums by examining specific content and posts [16]. The “Who” category captured the type of website (eg, blog post, news article) and the URL, which helped us determine the type of websites that were being shared. The “What” category was used to describe what content the website was sharing. This category was crucial in helping us determine the messages of the website. “When” noted the date the website content was published to determine whether links are being shared on the Facebook Page instantaneously or randomly. In the “Why” category, we noted any comments or statements made by the Facebook Page when sharing the linked website. Noting these statements in this section helped give us a better idea of the purpose behind sharing these websites and what the administrators of the page hoped to achieve by sharing these links with their audience. “Opportunity” was a crucial category in helping us note the amount of “reactions,” “shares,” and “comments” on the Facebook post sharing the link. By noting the reactions, we were able to assert which type of links get the most reactions and replies from the audience.

Results

Myths

The claims made by the authors on the Facebook Pages were diverse and ranged from questioning the ethics of administration to a total disregard of the benefits of immunization. Demographics of the overseers of the Facebook Page or users cannot be known as Pages can be accessed worldwide; however, given the posts about the Centers for Disease Control and Prevention (CDC) and current events in the United States, we conjecture that the users and majority of commentators are from the United States. Claims under “Myths” numbered far greater than those listed under “Truths.” Claims are listed in order of greatest to least in number.

Claim 1: “Vaccines Fail”

Several users on all Facebook Pages expressed the concern that vaccines are not 100% safe and people should opt to not vaccinate. References were made to the recent outbreaks of measles in the United States, and users claimed that most affected individuals were already vaccinated. The CDC reports that a majority of measles-affected individuals were unvaccinated [17]. Claims were made that the measles/mumps/rubella (MMR) vaccine was failing, and the need for the DTaP vaccine for tetanus was disregarded, as tetanus is not a communicable disease.

Claim 2: “Vaccine Schedules are Overwhelming and Spark Autoimmunity”

Users expressed concerns with the number of immunizations being added to child schedules by the CDC and with multiple vaccines given at one time. Parents were concerned about vaccines overstimulating the immune system. Some parents claimed to go with “alternative” immunization schedules in collaboration with their health care providers [18]. This included

giving fewer vaccines at once and skipping vaccines deemed “not important” by the parents. Users also expressed concerns about the differences in child vaccine schedules among different countries and used it as a reason not to vaccinate against certain diseases (eg, the United Kingdom does not vaccinate against varicella).

Claim 3: “Vaccines Contain Harmful Adjuvants”

Adjuvants used in vaccines have been under heavy scrutiny on all Facebook Pages. Adjuvants are added to a vaccine to strengthen its ability to stimulate the immune system [19]; however, they are believed to be responsible for causing a variety of diseases such as cancer, infertility, Alzheimer’s, and autism. Each vaccine has been linked to its own set of mythical consequences from contained adjuvants (see Table 1). Table 1 lists the most popular vaccines discussed on the Facebook Pages with the most popular adjuvant in each vaccine that is accused of causing harm. The table highlights the effect of the disease on unprotected individuals to reinforce the dangers of the infections prevented by immunization.

Table 1. Vaccines and their alleged consequences.

Diseases that can be prevented by immunization	Available vaccine(s)	Adjuvant in vaccine allegedly causing adverse effects	Prevailing myth(s)
Human papillomavirus	Gardasil, Gardasil 9	Polysorbate 80, aluminium	Infertility, premature ovarian failure, paralysis
Measles, mumps, rubella (MMR)	MMR	Aluminum, fetal bovine serum, recombinant human albumin	Autism, seizures, measles shedding from a vaccine, Alzheimer’s, lupus, aseptic meningitis
Diphtheria, pertussis, tetanus	Dtap, Tdap	Formaldehyde, polysorbate 80, bovine serum albumin	SIDS ^a , autism, vaccine-induced pertussis, neurodevelopmental problems, miscarriage, death
Polio	Inactivated poliovirus	Simian virus 40	Cancer, vaccine-induced paralysis

^aSIDS: sudden infant death syndrome.

The human papillomavirus vaccine was heavily linked to infertility and polycystic ovarian syndrome, MMR vaccine to autism and epilepsy, polio vaccine to cancer, and DTaP vaccine to sudden infant death syndrome (SIDS). Vaccines are accused of containing fetal cells as adjuvants, and claims are made that they influence the sexuality of teenagers and lead to homosexuality.

Truths

“Truths” contained information shared on Facebook that could be supported by peer-reviewed scientific evidence. Repeated concerns were raised over the efficacy of the flu vaccine. Flu vaccines are in production before the flu season begins (meetings in February for the Northern Hemisphere and in September for the Southern Hemisphere), and this information was shared on the Facebook Pages. Flu strains are predicted based on surveillance, laboratory, and clinical studies [20]. The flu vaccine’s effectiveness was questioned on all Facebook Pages; however, the effectiveness of the flu shot can change every year [21]. The Government of Canada states that the flu virus may change while the vaccine is in production: “Even when there is a less-than-ideal match or lower effectiveness against one virus, the seasonal flu shot can still provide protection against the remaining two or three viruses. If you do get the flu, the flu shot may reduce the severity of your symptoms” [21].

Another concern raised was “over-vaccinating” against pertussis (or whooping cough) as the vaccine is allegedly not effective. Schwartz et al [22] found that 4 years postimmunization, immunity to pertussis declined significantly, especially with the acellular vaccine as compared to the whole-cell vaccine. Booster shots during pregnancy or priming with the whole-cell vaccine are recommended to optimize pertussis control [22]. Use of the acellular vaccine instead of the whole-cell vaccine was another topic discussed on the Facebook Pages. A case-control study by Klein et al [23] found that, among teenagers who had received vaccines for pertussis at Kaiser Permanente Northern California, those immunized with whole-cell vaccine were more protected in outbreaks compared to teenagers who received the acellular pertussis vaccine.

Consequences

Autism is the most widely known affliction that allegedly implicates vaccines. The most popular consequences linked to vaccines also included SIDS, asthma, epilepsy, cancer, Alzheimer’s, miscarriage, infertility, and death (see Table 1). Testimonies from parents sharing information about the death of their children and posting their pictures are extremely popular on all the Pages. These have a profound effect on other viewers, as evidenced by their responses. Mothers have shared their hesitancy of vaccinating their children after viewing these posts.

Reactions to Current Measles Outbreaks

Measles outbreaks are at an all-time high in the United States, since the year 1992, with the numbers of cases growing. To achieve herd immunity for measles, 95% of the population must be immune to the infection [24]. Outbreaks in communities that are unvaccinated in New York account for more than 75% of the cases, with the majority affecting Orthodox Jewish communities where immunization rates are low. All Facebook Pages discussed the current coverage of measles outbreaks; however, 2 of the 4 Pages we examined posted more frequently about the mainstream media coverage of the outbreaks. Reactions to outbreaks included denial of events, accusing mainstream media of falsifying reports, and claiming that most individuals spreading the infection were vaccinated. While a vaccinated individual could contract measles, the chances are much lower compared to those for unvaccinated individuals, and the disease presents in a milder form [21].

Website Data

Website links shared on the Facebook Pages were followed. Data were also collected from January 2019 to May 2019. Website information was categorized into Who, What, When, Why, and Opportunity.

“Who”

We found that the shared website links were predominately blog posts coming from antivaccine activists. The most popular website shared on all the Pages was Green Med Info [25]. The author, Sayer Ji, is a self-proclaimed expert on the rights and wrongs of immunization and supports alternative medicine [25]. Other types of shared websites included news article, testimonials, and studies. Robert Kennedy is a huge supporter of antivaccine sentiments. His blog website was shared numerous times on all Pages.

“What”

We found that the themes emerging from shared content on the websites varied. These included stories of vaccinated individuals getting the infection they were vaccinated against, testimonies from mothers whose children allegedly died postimmunization, accusations towards the government and physicians for promoting vaccines to make money, condemnation of mandatory vaccine bills and laws, “expert” testimonies on dangers of immunization, promotion of naturopathic medicine, and denial of the harm of illnesses that vaccines protect from. Some websites claimed that childhood infection with measles provides protection from cardiac disease in adult life and women will be protected from ovarian cancer, but the sites do not produce sufficient evidence to support these claims.

“When”

Information on the vast majority of the websites had been published within the last month; however, for sites that were not current, they were at least published in the last decade. The growth of these Pages in the last decade supports the fact that antivaccine content has increased with the use of social media and the internet [6,26]. The “post” or “share” date on the Facebook Pages compared to the original publication date of the website was within 1 week for most posts on 3 of the 4

Pages. We found that one Facebook Page in particular shared website links published 1 or 2 years before current events, but still received lots of support from followers.

“Why”

The main reasons for sharing a website link were either to promote or condemn its content. The majority of website links were supported and shared as a way of endorsing the antivaccine information. We do not have reason to believe that any of the shared website links were vetted for scientific evidence or truthfulness; instead, content that would have a profound effect on viewers was shared. This included “new” studies and information such as the “benefits” of getting an infection.

“Opportunity”

We found that comments, “reactions,” and “shares” on the Facebook posts sharing the website link did not show any specific trend. The number of responses varied heavily; this could be attributed to the number of online users or personal interests. Therefore, we cannot make a conclusion on whether any specific topics sparked user interest; however, a news article shared on one of the Pages about Kailyn Lowry, an actress, had the highest number of “reactions” compared to any other website link shared on one of the Facebook Pages. This is significant, as celebrities have the platform to influence many people across different geographical areas just by sharing their personal beliefs [9,27].

Discussion

Principal Findings

The analysis of the Facebook Pages led to emerging themes from the ongoing discussion among the users and their use of Facebook as their platform to promote their anti-vaccine beliefs: (1) forming an online “community” consisting of like-minded individuals and similar beliefs, (2) the widespread reach of anti-vaccine messages, and (3) debating the ethics of mandatory immunization and content moderation.

The majority of the online population of users on the Facebook Page were likely from the United States. We noticed there was a huge appreciation of community and support for one another. For example, if anyone posting antivaccine content was criticized or condemned, other users would step up to support them in the comments of posts. There was a tremendous amount of support in mother-to-mother communication. A social media analysis conducted by Gruzd and Haythornthwaite [28] analyzed a 1-month sample of Twitter messages to trace interaction via social media and understand “how a community is formed and maintained online.” The study found that network analysis can facilitate understanding of “what, and who, compromises and sustains a network...” [28]. Gruzd and Haythornthwaite [28] found that active participation and attention to others were extremely significant aspects of building an online community. This finding translates very well to our analysis as aforementioned: The sharing of pictures and stories of children who were allegedly afflicted by vaccines was very popular, and mothers tended to gather and demonstrate support for one another in such cases. Supporting one another in their “time of

need” and defending their collective viewpoints helped foster a sense of community among each other [29].

A very significant finding was the raising of money for private autopsies postdeath of a child from SIDS. Users believe that immunization can cause SIDS; therefore, when the cause of death is not officially linked to vaccines, users on these Facebook Pages collected donations for private autopsies, with the amounts ranging in the thousands. There was little to no follow-up from parents who received this money on whether the autopsy was done, and no follow-up included medical proof of immunization being linked to SIDS. Users on Facebook who support these Pages are a highly tight-knit community, who have limited trust in government authorities and medical professionals [30]. Users on one of the Facebook Pages examined in this research encouraged a mother to not fill a prescription for Tamiflu after her son had been diagnosed with influenza and was running a high fever and had a seizure [31]. None of the comments on the post encouraged the mother to seek medical help and fill the prescription. The mother instead opted to treat with natural remedies such as peppermint oil, vitamin C, and lavender [31]. The users on Facebook also suggested the use of home remedies such as breastmilk, thyme, and elderberry to treat her child — none of which are recommended treatment for influenza — and the child eventually died 4 days later at the hospital [31]. This case, in particular, highlights the trust and confidence users of these Pages are placing upon each other.

This relationship among users who have likely never even met each other can be incredibly difficult to infiltrate and change, as they share a common ground of strong values and beliefs. We must focus resources on individuals who are undecided and caught in the middle of the debate [11]. Interventions must be community-based, and education and information on vaccines must be encouraged by alike members in the community (such as parent groups) [32]. As health care professionals, we must become informed on adjuvants and how they impact the body (along with other concerns noted in the Results section) and therefore be equipped to answer questions parents may have to build trust [33]. It is incredibly important for health care personnel to recognize and understand this problem [33]. Vaccines are one of the largest defenses we have against communicable diseases, and we must continue to educate and attempt to change the attitudes surrounding this important issue.

Widespread Reach of Antivaccine Messages

Antivaccine sentiments no longer belong to a small group of people; instead, they have global implications [5,11,34]. Three of the 4 Facebook Pages have 100,000 to 135,000 likes, and the most popular website shared on the Facebook Pages — Green Med Info — claims to have 500,000 monthly visitors [25]. Our research of the Pages uncovered how detrimental these campaigns can be in underdeveloped nations of the world. Pakistan is one of 3 countries that has failed to eradicate polio transmission [35]. The spread of vaccine misinformation through the availability of smartphones and social media is encouraging a public health threat in one of the most vulnerable nations of the world [34,35]. Not only has misinformation threatened Pakistan’s public health but the unauthorized immunization

campaign directed by the Central Intelligence Agency in an attempt to locate Osama Bin Laden has broken the trust between locals and foreign public health efforts [36]. Another example of mistrust of western medicine in the developing world is Nigeria, where Islamic militant groups believe that immunization is a ploy to sterilize Muslims [37].

Measles outbreaks have been on the rise globally, increasing by 30% from 2016 to 2017 [38]. These outbreaks correlate heavily with whether citizens trust vaccines. For example, France experienced measles outbreaks, with 1 in 3 of their citizens believing that vaccines are not safe [38]. Currently, the COVID-19 pandemic has taken the world by storm, and researchers and the general public are eager for a vaccine to help flatten the curve of the disease. When the time comes to distribute a vaccine for this virus (or any uncontrollable communicable disease), we must not only promote the vaccine to those who trust immunization but also promote targeted interventions for users of these Pages who refuse to vaccinate by increasing opportunity for dialogue and creating safe spaces [32,33]. Our recommendation for institutions includes adding and enhancing education on vaccines and immunization for future health care professionals, such as doctors, nurses, and dentists, to address concerns of users on these Facebook Pages [33,39].

Debating the Ethics of Mandatory Immunization and Content Moderation

A focal point of discussion on Facebook posts, website shares, and the comments section was the ethics of mandatory immunization laws [40]. Antivaccine groups are heavily against the passing of any bill that supports mandatory immunization [41]. Vaccine Choice Canada — one of Canada’s largest antivaccine organizations — claims they are prepared to fight New Brunswick’s 2019 proposed bill that will not allow children to attend public school without proof of immunization [42]. This nightmare for antivaccine organizations has already become a reality for those living in the state of California in the United States. There were calls to action against the governments that propose mandatory immunization and consistent derogatory comments made against the governor of California for being an open vaccine supporter on Facebook. Users on Facebook urged others to join protests, sign petitions, and call government officials’ offices to discourage mandatory immunization. Users frequently cited the Constitution of the United States, claiming their rights as citizens of the country have been violated through these bills and laws.

The ethical debate has also included the censoring of content on social media websites. Facebook has claimed to not remove vaccine misinformation; however, they assured the public that they will make it less prominent [7,43,44]. This includes removing content from recommended groups and ranking posts with misinformation lower on the newsfeed [7,44]. Other social media sites that are moderating antivaccine content include YouTube, Pinterest, and Twitter. YouTube has stopped serving ads on any antivaccine-promoting video and attempted to make content on the benefits of immunization easier to find [45]. The WHO has applauded Pinterest for being a leader in removing vaccine misinformation from their website [44]. Pinterest has

one of the most rigorous restrictions on posting of vaccine misinformation, going as far as to block any searches with the terms “anti-vaccination” or “anti-vax” [44].

Conclusion

The antivaccine campaign has unfortunately used social media as a vessel to spread misinformation to users, especially parents [4-7,9,11-13,26,27,29,30,32,37,40,41,46,47]. As vaccine hesitancy increases, we increase the risk of a public health crisis and lessen our chances of controlling crises like the COVID-19 pandemic. Although users on Facebook have mentioned “Truths,” the number of “Myths” supersede these truths, and the benefits of immunization greatly outweigh the risk. We must understand the local-global implications of allowing preventable diseases to make a comeback. Health care providers deal directly with members of the public who are uncertain about immunization, and it becomes their job to be informed on users’ common misconceptions [33,39]. Fake news travels faster than truth, building momentum [48]; therefore, targeted promotion

of vaccines that address specific claims on the internet is warranted.

Limitations of this study include the ever-dynamic nature of the internet, with the freedom for administrators and users to remove posts as desired, and the time constraints in which we studied the Facebook Pages. The social media audit template used to organize and categorize data has previously not been used in studying data for the interpretation of messages. We also cannot be certain that each different follower of the Page is a different individual, as one person may hold many accounts using different email addresses. This analysis focuses only on Facebook, which, as aforementioned, has a less scrutinizing approach to removing antivaccine content; therefore, analysis of other websites such as Twitter, YouTube, and Pinterest is warranted to compare the type of content and spread of readership. The worldview of both authors is that of nurses and health care providers, and this article has been written with a pro-immunization point of view.

Acknowledgments

We gratefully acknowledge the Program for Undergraduate Research Experience at the University of Calgary for funding this research project.

Conflicts of Interest

None declared.

References

1. Immunization. World Health Organization. 2019 Dec 05. URL: <https://www.who.int/news-room/facts-in-pictures/detail/immunization> [accessed 2020-04-29]
2. Measles in Canada. Government of Canada. 2019 Apr 01. URL: <https://www.canada.ca/en/public-health/services/diseases/measles/measles-in-canada.html> [accessed 2019-08-08]
3. Poliomyelitis (Polio): For health professionals. Government of Canada. 2018 Oct 18. URL: <https://www.canada.ca/en/public-health/services/diseases/poliomyelitis-polio/health-professionals.html> [accessed 2020-04-30]
4. Ten threats to global health in 2019. World Health Organization. 2019 Mar 21. URL: <https://www.who.int/vietnam/news/feature-stories/detail/ten-threats-to-global-health-in-2019> [accessed 2019-08-30]
5. Benecke O, DeYoung SE. Anti-Vaccine Decision-Making and Measles Resurgence in the United States. *Glob Pediatr Health* 2019;6:2333794X19862949. [doi: [10.1177/2333794X19862949](https://doi.org/10.1177/2333794X19862949)] [Medline: [31384629](https://pubmed.ncbi.nlm.nih.gov/31384629/)]
6. Stahl J, Cohen R, Denis F, Gaudelus J, Martinot A, Lery T, et al. The impact of the web and social networks on vaccination. New challenges and opportunities offered to fight against vaccine hesitancy. *Med Mal Infect* 2016 May;46(3):117-122. [doi: [10.1016/j.medmal.2016.02.002](https://doi.org/10.1016/j.medmal.2016.02.002)] [Medline: [26987960](https://pubmed.ncbi.nlm.nih.gov/26987960/)]
7. Caron C. Facebook Announces Plan to Curb Vaccine Misinformation. *The New York Times*. 2019 Mar 07. URL: <https://www.nytimes.com/2019/03/07/technology/facebook-anti-vaccine-misinformation.html> [accessed 2020-09-24]
8. Clement J. Most popular social networks worldwide as of July 2020, ranked by number of active users. Statista. 2020 Aug 21. URL: <https://www.statista.com/statistics/272014/global-social-networks-ranked-by-number-of-users/> [accessed 2020-09-24]
9. Hussain A, Ali S, Ahmed M, Hussain S. The Anti-vaccination Movement: A Regression in Modern Medicine. *Cureus* 2018 Jul 03;10(7):e2919 [FREE Full text] [doi: [10.7759/cureus.2919](https://doi.org/10.7759/cureus.2919)] [Medline: [30186724](https://pubmed.ncbi.nlm.nih.gov/30186724/)]
10. Martin B. Texas Anti-Vaxxers Fear Mandatory COVID-19 Vaccines More Than the Virus Itself. *TexasMonthly*. 2020 Mar 18. URL: <http://www.texasmonthly.com/news/texas-anti-vaxxers-fear-mandatory-coronavirus-vaccines/> [accessed 2020-09-24]
11. Johnson N, Velásquez N, Restrepo N, Leahy R, Gabriel N, El Oud S, et al. The online competition between pro- and anti-vaccination views. *Nature* 2020 Jun;582(7811):230-233 [FREE Full text] [doi: [10.1038/s41586-020-2281-1](https://doi.org/10.1038/s41586-020-2281-1)] [Medline: [32499650](https://pubmed.ncbi.nlm.nih.gov/32499650/)]
12. WHO fights a pandemic besides coronavirus: An "infodemic". *The New York Times*. 2020 Feb 06. URL: <https://www.nytimes.com/2020/02/06/health/coronavirus-misinformation-social-media.html> [accessed 2020-09-24]

13. Surge of virus misinformation stumps Facebook and Twitter. The New York Times. 2020 Mar 08. URL: <https://www.nytimes.com/2020/03/08/technology/coronavirus-misinformation-social-media.html> [accessed 2020-09-24]
14. Frequently Asked Flu Questions 2018-2019 Influenza Season. Centers for Disease Control and Prevention. 2019 Jan 10. URL: <https://www.cdc.gov/flu/about/season/flu-season-2018-2019.htm> [accessed 2020-09-24]
15. Quesenberry K. Social media not meeting expectations? Perform a social media audit. 2017 Dec 18. URL: <https://www.postcontrolmarketing.com/social-media-audit/> [accessed 2020-09-24]
16. Quesenberry KA. Conducting a Social Media Audit. Harvard Business Review. 2015 Nov 18. URL: <https://hbr.org/2015/11/conducting-a-social-media-audit> [accessed 2020-09-24]
17. Centers for Disease Control and Prevention. Measles cases in 2019. Measles Cases and Outbreaks. 2020 Aug 19. URL: <https://web.archive.org/save/https://www.cdc.gov/measles/cases-outbreaks.html> [accessed 2020-09-24]
18. Rodriguez NJ. Vaccine-Hesitant Justifications: "Too Many, Too Soon," Narrative Persuasion, and the Conflation of Expertise. *Glob Qual Nurs Res* 2016;3:2333393616663304. [doi: [10.1177/2333393616663304](https://doi.org/10.1177/2333393616663304)] [Medline: [28508015](https://pubmed.ncbi.nlm.nih.gov/28508015/)]
19. Christensen D. Vaccine adjuvants: Why and how. *Hum Vaccin Immunother* 2016 Oct 02;12(10):2709-2711 [FREE Full text] [doi: [10.1080/21645515.2016.1219003](https://doi.org/10.1080/21645515.2016.1219003)] [Medline: [27551808](https://pubmed.ncbi.nlm.nih.gov/27551808/)]
20. Selecting viruses for the seasonal influenza vaccine. Centers for Disease Control and Prevention. 2018 Sep 04. URL: <https://www.cdc.gov/flu/prevent/vaccine-selection.htm> [accessed 2020-09-24]
21. Flu (influenza): Get your flu shot. Government of Canada. 2019 Aug 09. URL: <https://www.canada.ca/en/public-health/services/diseases/flu-influenza/get-your-flu-shot.html> [accessed 2020-09-24]
22. Schwartz KL, Kwong JC, Deeks SL, Campitelli MA, Jamieson FB, Marchand-Austin A, et al. Effectiveness of pertussis vaccination and duration of immunity. *CMAJ* 2016 Nov 01;188(16):E399-E406. [doi: [10.1503/cmaj.160193](https://doi.org/10.1503/cmaj.160193)] [Medline: [27672225](https://pubmed.ncbi.nlm.nih.gov/27672225/)]
23. Klein NP, Bartlett J, Fireman B, Rowhani-Rahbar A, Baxter R. Comparative effectiveness of acellular versus whole-cell pertussis vaccines in teenagers. *Pediatrics* 2013 Jun 20;131(6):e1716-e1722. [doi: [10.1542/peds.2012-3836](https://doi.org/10.1542/peds.2012-3836)] [Medline: [23690518](https://pubmed.ncbi.nlm.nih.gov/23690518/)]
24. Funk S. Critical immunity thresholds for measles elimination. 2017 Oct 19. URL: https://www.who.int/immunization/sage/meetings/2017/october/2_target_immunity_levels_FUNK.pdf [accessed 2020-09-24]
25. GreenMedinfo. 2020. URL: <https://www.greenmedinfo.com/> [accessed 2020-09-24]
26. Ward JK, Peretti-Watel P, Verger P. Vaccine criticism on the Internet: Propositions for future research. *Hum Vaccin Immunother* 2016 Jul 02;12(7):1924-1929 [FREE Full text] [doi: [10.1080/21645515.2016.1146430](https://doi.org/10.1080/21645515.2016.1146430)] [Medline: [26900646](https://pubmed.ncbi.nlm.nih.gov/26900646/)]
27. Smith TC. Vaccine Rejection and Hesitancy: A Review and Call to Action. *Open Forum Infect Dis* 2017;4(3):ofx146 [FREE Full text] [doi: [10.1093/ofid/ofx146](https://doi.org/10.1093/ofid/ofx146)] [Medline: [28948177](https://pubmed.ncbi.nlm.nih.gov/28948177/)]
28. Gruzd A, Haythornthwaite C. Enabling community through social media. *J Med Internet Res* 2013 Oct 31;15(10):e248 [FREE Full text] [doi: [10.2196/jmir.2796](https://doi.org/10.2196/jmir.2796)] [Medline: [24176835](https://pubmed.ncbi.nlm.nih.gov/24176835/)]
29. Vrdelja M, Kraigher A, Vercic D, Kropivnik S. The growing vaccine hesitancy: exploring the influence of the internet. *Eur J Public Health* 2018 Oct 01;28(5):934-939. [doi: [10.1093/eurpub/cky114](https://doi.org/10.1093/eurpub/cky114)] [Medline: [29982349](https://pubmed.ncbi.nlm.nih.gov/29982349/)]
30. Orr D, Baram-Tsabari A, Landsman K. Social media as a platform for health-related public debates and discussions: the Polio vaccine on Facebook. *Isr J Health Policy Res* 2016;5:34 [FREE Full text] [doi: [10.1186/s13584-016-0093-4](https://doi.org/10.1186/s13584-016-0093-4)] [Medline: [27843544](https://pubmed.ncbi.nlm.nih.gov/27843544/)]
31. Zadrozny B. On Facebook, anti-vaxxers urged a mom not to give her son Tamiflu. He later died. NBC News. 2020 Feb 07. URL: <https://www.nbcnews.com/tech/social-media/facebook-anti-vaxxers-pushed-mom-not-give-her-son-tamiflu-n1131936> [accessed 2020-09-24]
32. Steffens M, Dunn AG, Wiley KE, Leask J. How organisations promoting vaccination respond to misinformation on social media: a qualitative investigation. *BMC Public Health* 2019 Oct 23;19(1):1348 [FREE Full text] [doi: [10.1186/s12889-019-7659-3](https://doi.org/10.1186/s12889-019-7659-3)] [Medline: [31640660](https://pubmed.ncbi.nlm.nih.gov/31640660/)]
33. Paterson P, Meurice F, Stanberry LR, Glismann S, Rosenthal SL, Larson HJ. Vaccine hesitancy and healthcare providers. *Vaccine* 2016 Dec 20;34(52):6700-6706 [FREE Full text] [doi: [10.1016/j.vaccine.2016.10.042](https://doi.org/10.1016/j.vaccine.2016.10.042)] [Medline: [27810314](https://pubmed.ncbi.nlm.nih.gov/27810314/)]
34. Dubé E, Gagnon D, Nickels E, Jeram S, Schuster M. Mapping vaccine hesitancy--country-specific characteristics of a global phenomenon. *Vaccine* 2014 Nov 20;32(49):6649-6654 [FREE Full text] [doi: [10.1016/j.vaccine.2014.09.039](https://doi.org/10.1016/j.vaccine.2014.09.039)] [Medline: [25280436](https://pubmed.ncbi.nlm.nih.gov/25280436/)]
35. Saifi S, Shah S. Pakistan's anti-vaccination movement leads to string of deadly attacks. CNN. 2019 Apr 26. URL: <https://www.cnn.com/2019/04/26/health/polio-worker-deaths-pakistan-intl/index.html> [accessed 2020-09-24]
36. He led the CIA to bin Laden- and unwittingly fueled a vaccine backlash. 2015 Feb 27. URL: <https://www.nationalgeographic.com/news/2015/02/150227-polio-pakistan-vaccination-taliban-osama-bin-laden/> [accessed 2020-09-24]
37. Vaccines: Low trust in vaccination 'a global crisis'. BBC News. 2019 Jun 19. URL: <https://www.bbc.com/news/health-48512923> [accessed 2020-09-24]
38. How anti-vaccine movements threaten global health. BBC News. 2019 Jun 20. URL: <https://www.bbc.com/news/health-48585036> [accessed 2020-09-24]

39. Esposito S, Principi N, Cornaglia G, ESCMID Vaccine Study Group (EVASG). Barriers to the vaccination of children and adolescents and possible solutions. *Clin Microbiol Infect* 2014 May;20 Suppl 5(25):25-31 [FREE Full text] [doi: [10.1111/1469-0691.12447](https://doi.org/10.1111/1469-0691.12447)] [Medline: [24354949](https://pubmed.ncbi.nlm.nih.gov/24354949/)]
40. Williamson L, Glaab H. Addressing vaccine hesitancy requires an ethically consistent health strategy. *BMC Med Ethics* 2018 Oct 24;19(1):84 [FREE Full text] [doi: [10.1186/s12910-018-0322-1](https://doi.org/10.1186/s12910-018-0322-1)] [Medline: [30355355](https://pubmed.ncbi.nlm.nih.gov/30355355/)]
41. Whelan AM. Lowering the Age of Consent: Pushing Back against the Anti-Vaccine Movement. *J Law Med Ethics* 2016 Sep;44(3):462-473. [doi: [10.1177/1073110516667942](https://doi.org/10.1177/1073110516667942)] [Medline: [27587450](https://pubmed.ncbi.nlm.nih.gov/27587450/)]
42. Brown S. Anti-vaccination group to challenge New Brunswick mandatory immunization. *Global News*. 2019 Aug 28. URL: <https://globalnews.ca/news/5824507/vaccine-new-brunswick-hearings-day-two/> [accessed 2020-09-24]
43. Pagoto S, Waring ME, Xu R. A Call for a Public Health Agenda for Social Media Research. *J Med Internet Res* 2019 Dec 19;21(12):e16661 [FREE Full text] [doi: [10.2196/16661](https://doi.org/10.2196/16661)] [Medline: [31855185](https://pubmed.ncbi.nlm.nih.gov/31855185/)]
44. Cohen E, Bonifield J. Facebook to get tougher on anti-vaxers. *CNN*. 2019 Feb 26. URL: <https://www.cnn.com/2019/02/25/health/facebook-anti-vaccine-content/index.html> [accessed 2020-09-24]
45. YouTube takes ads off 'anti-vax' video channels. *BBC News*. 2019 Feb 25. URL: <https://www.bbc.com/news/technology-47357252> [accessed 2020-09-24]
46. Burki T. Vaccine misinformation and social media. *The Lancet Digital Health* 2019 Oct;1(6):e258-e259. [doi: [10.1016/S2589-7500\(19\)30136-0](https://doi.org/10.1016/S2589-7500(19)30136-0)]
47. Kata A. A postmodern Pandora's box: anti-vaccination misinformation on the Internet. *Vaccine* 2010 Feb 17;28(7):1709-1716. [doi: [10.1016/j.vaccine.2009.12.022](https://doi.org/10.1016/j.vaccine.2009.12.022)] [Medline: [20045099](https://pubmed.ncbi.nlm.nih.gov/20045099/)]
48. Shu K, Sliva A, Wang S, Tang J, Liu H. Fake News Detection on Social Media. *SIGKDD Explor. Newsl* 2017 Sep;19(1):22-36. [doi: [10.1145/3137597.3137600](https://doi.org/10.1145/3137597.3137600)]

Abbreviations

CDC: Centers for Disease Control and Prevention

MMR: measles/mumps/rubella

SIDS: sudden infant death syndrome

WHO: World Health Organization

Edited by E Borycki; submitted 25.03.20; peer-reviewed by H Akram, A McLean, E Da Silva, M Toledo; comments to author 13.04.20; revised version received 21.05.20; accepted 01.07.20; published 20.10.20.

Please cite as:

Dhaliwal D, Mannion C

Antivaccine Messages on Facebook: Preliminary Audit

JMIR Public Health Surveill 2020;6(4):e18878

URL: <http://publichealth.jmir.org/2020/4/e18878/>

doi: [10.2196/18878](https://doi.org/10.2196/18878)

PMID: [33079072](https://pubmed.ncbi.nlm.nih.gov/33079072/)

©Dhamanpreet Dhaliwal, Cynthia Mannion. Originally published in *JMIR Public Health and Surveillance* (<http://publichealth.jmir.org>), 20.10.2020. This is an open-access article distributed under the terms of the Creative Commons Attribution License (<https://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in *JMIR Public Health and Surveillance*, is properly cited. The complete bibliographic information, a link to the original publication on <http://publichealth.jmir.org>, as well as this copyright and license information must be included.

Viewpoint

Human-Animal Interaction and the Emergence of SARS-CoV-2

Asma Hassani¹, MMedSci; Gulfaraz Khan¹, PhD, FRCPath

Department of Medical Microbiology and Immunology, College of Medicine and Health Sciences, United Arab Emirates University, Al Ain, United Arab Emirates

Corresponding Author:

Gulfaraz Khan, PhD, FRCPath

Department of Medical Microbiology and Immunology

College of Medicine and Health Sciences

United Arab Emirates University

Tawam Hospital Campus

Al Ain

United Arab Emirates

Phone: 971 3 7137482

Email: g_khan@uaeu.ac.ae

Abstract

The COVID-19 pandemic has affected all sectors of society, from health and economics to socialization and travel. The level and extent of this impact are unprecedented. Although the cause of COVID-19 was quickly identified to be a new coronavirus (SARS-CoV-2), the world was poorly prepared for preventing its spread. One important pillar of preparedness is surveillance of the sources of emerging pathogens and responding appropriately to prevent their spread in the human population. The ever-increasing interaction between humans and animals is one leading factor in facilitating the emergence of new pathogens. In this viewpoint, we discuss the possibility of the zoonotic origin of SARS-CoV-2, highlight the importance of understanding human-animal interaction to improve preparedness for future outbreaks, and outline recommendations for prevention.

(*JMIR Public Health Surveill* 2020;6(4):e22117) doi:[10.2196/22117](https://doi.org/10.2196/22117)

KEYWORDS

zoonosis; human-animal interface; COVID-19; SARS-CoV-1; outbreak; virus; transmission; pathogen; emergence; reservoir

Introduction

Currently, the world is battling a pandemic caused by a virus previously undocumented in humans. The new virus, SARS-CoV-2, was identified as the cause of COVID-19. The infection presented with a broad spectrum of symptoms ranging from mild disease to organ failure and death. Similar to severe acute respiratory syndrome coronavirus (SARS-CoV-1) and the Middle East respiratory syndrome coronavirus (MERS-CoV), SARS-CoV-2 is a positive-sense, single-stranded ribonucleic acid (+ssRNA) member of the β -coronavirus genus. However, compared to SARS-CoV-1, SARS-CoV-2 appears to be more efficient in human-to-human transmission [1,2]. The fact that the global spread of the virus outpaced infection control measures has raised concerns about our preparedness to face new viral threats. In this viewpoint, we discuss the potential zoonotic origin of SARS-CoV-2 and revisit the main elements that promote the emergence and spread of new infectious diseases. We also highlight the factors that instigate the rise in new human pathogens and outline recommendations for prevention.

SARS-CoV-2 and the Possibility of an Animal-to-Human Spillover Event

Despite the uncertainty about where and when SARS-CoV-2 originated, the genome sequencing of isolates from early cases indicate an animal origin, with bats being suggested as the most probable source [3-6]. *In silico* evaluation of a SARS-CoV-2 receptor, angiotensin-converting enzyme 2 (ACE2), indicates that the current pandemic may be caused by a virus with a broad range of hosts, including swine, civets, cats, cows, buffalo, sheep, pigeon, and pangolins [7]. The susceptibility and permissibility of these animals, however, are yet to be tested and proven. One or more domesticated and wild animals have been proposed as an intermediate host for SARS-CoV-2, aiding the spillover to humans [8-11]. Determination of the seroprevalence of SARS-CoV-2 and experimental infection in these animals will help to clarify which, if any, may be involved in the emergence of SARS-CoV-2 [5,7,12]. Moreover, it is also speculated that SARS-CoV-2 could be a result of the recombination of two viruses that circulate in animals living or placed in close proximity [13,14].

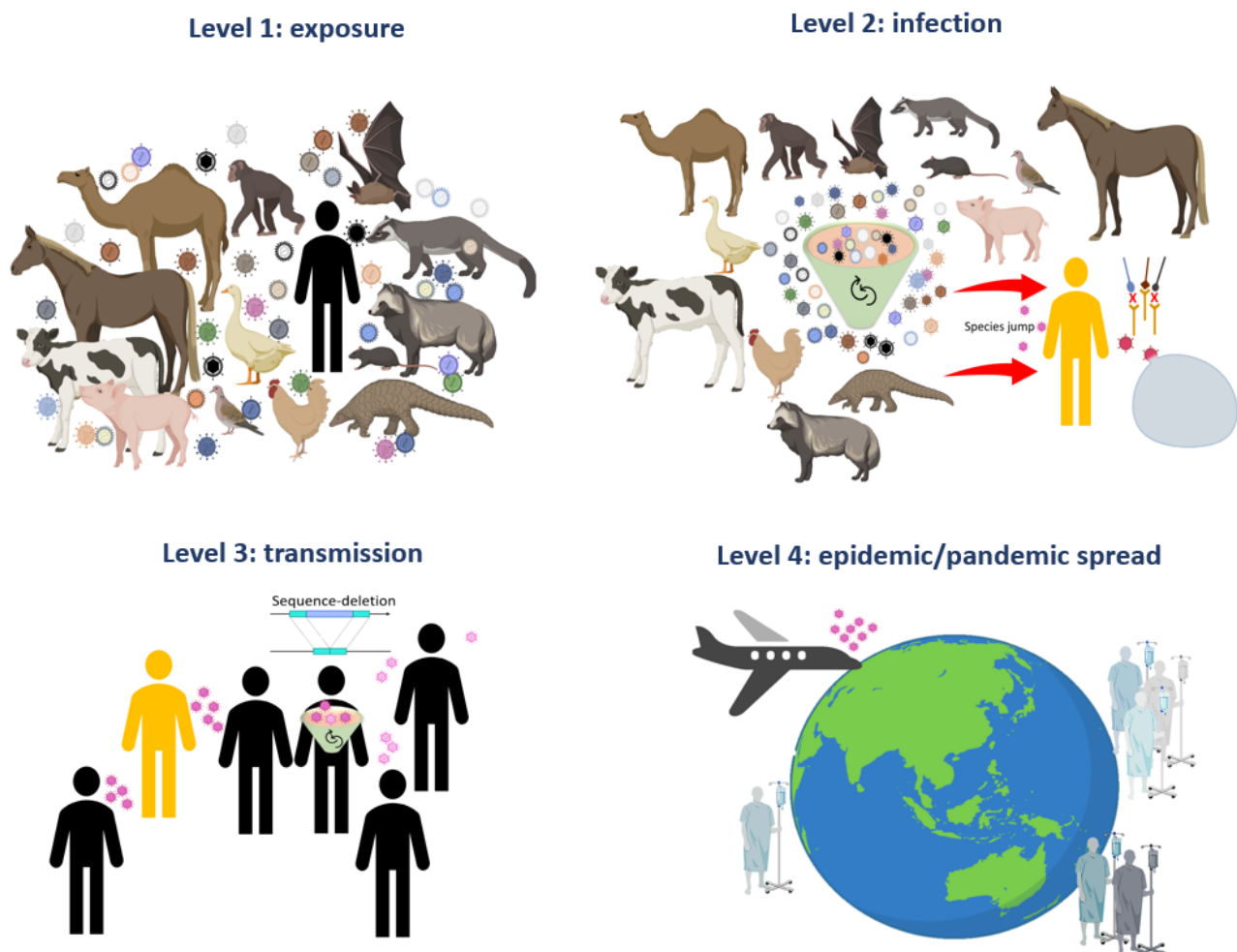
If SARS-CoV-2 is the result of a cross-species spillover, the conditions that facilitated the adaptation of SARS-CoV-2 to humans remain unknown [15]. If prejump adaptation occurred in an intermediate host, then SARS-CoV-2 would have undergone genetic refinement in one or more animal species that were spatiotemporally aggregated and in constant contact with humans. The intermediate species is likely to carry an ACE2 receptor that closely clusters with that of humans. If viral adaptation occurred after the spillover event, then continuous passage of the virus from person to person would provide the necessary natural selection opportunities. This would be a realistic assumption given the relatively long incubation (and infectiousness) period, which allows for unnoticeable transmission via a respiratory route. The postadaptation progeny virus can be somewhat genetically distinct from the original virus that made the initial animal-to-human jump [4]. For instance, examining cases of the 2002 severe acute respiratory syndrome (SARS) outbreak revealed that SARS-CoV-1 isolates from early cases (2002) differed from viral isolates obtained from later cases (2003). The viral spike (S) protein involved in binding to the ACE2 receptor showed reduced binding affinity

in later viral isolates compared to early isolates [16]. Additionally, a sequence of 29 nucleotides in the C-terminus of the viral genome was deleted in viral isolates from later cases, and this deletion is believed to have occurred through viral adaptation to a human host [17].

Revisiting the Four Levels of Emerging Infectious Diseases

The dramatic rise in human activities in animal farming, the livestock and poultry industries, live-animal markets, and bushmeat has dangerously increased human-animal and animal-animal contact rates [18]. As a result, and combined with careless practices of animal handling, pathogen attack rates have surged substantially. Animals (wildlife and domestic) have gained much attention as candidate reservoirs for numerous, often serious, emerging viral diseases including monkeypox, Ebola, HIV, West Nile virus, rabies, and A/H5N1. The complex link between humans, animals, and emerging pathogens can be simplified in a 4-level model (Figure 1).

Figure 1. The four-level model of pathogen emergence. Bushmeat production, poultry and livestock industries, and live-animal markets warrant frequent close animal-human and animal-animal contact and increase exposure to pathogens circulating in different species. Frequent exposure (level 1) can turn into a productive infection (level 2), given the necessary viral adaptation has taken place to make humans susceptible. By passing through humans, the new virus may undergo further adaptation. Pandemic emergence necessitates an efficient human-to-human transmission for sustained propagation. Fast human movement across the globe amplifies the chain of transmission. Efforts should be directed at preventing level 1 (exposure) to significantly decrease the chances of pathogen emergence.



At level 1 (or exposure), the human host encounters the “new” pathogen (eg, virus). Handling animals promotes such encounters. This initial encounter can happen independently of the human’s susceptibility to the virus. Susceptibility means that the host has suitable receptor(s) for viral attachment. The number of viruses to which we are exposed is unknown, but given the profound interaction we have with our environment, we can only assume that the exposure is much higher than we can possibly recognize. At level 2 (or infection), the human-virus encounter becomes fruitful. The human host becomes susceptible and part of the viral lifecycle. Over a thousand pathogenic species have successfully achieved this level. In fact, within the last four decades, new human pathogens have been identified at a rate of more than 3 annually. The majority of these pathogens were viruses [19]. This predominance of viruses as causative agents of emerging diseases is partially attributed to enhanced approaches in viral detection and increased viral mutation rates occurring at relatively short spans [20]. Moreover, almost three-quarters of new human viral infections are attributed to viruses of animal origin that crossed the species barrier [21,22]. Indeed, viruses of nonhuman primates and bats are associated with a high relative risk of emergence [23]. At level 3 (or transmission), the new virus can spread from one person to another. This is generally indicated by the basic reproduction number (R_0), a measure that estimates the number of secondary infections in “naïve” susceptible population [24]. A pathogen with an $R_0 > 1$ has a better chance of widespread transmission leading to level 4. At level 4 (epidemic/pandemic spread), efficient human-to-human transmission generates sustained propagation. This usually happens without the need for new animal-to-human cross-species transmission events [25].

Factors That Spark Animal-to-Human Spillover

The cascade of events that led to the emergence of SARS-CoV-2 are likely to be complicated, but there seems to be a belief that humans at some point were exposed to the new virus, probably directly from bats (the reservoir?) [26], or indirectly through an intermediate and/or amplifying host(s) (wild and/or farm animals) [5,27,28]. Indeed, increased aggregation of people, wildlife, and domestic animals in spatiotemporal closeness, and the various ways of handling animal products, could have increased the exposure rate (level 1). In order to understand what could have precipitated this cross-species transmission (level 2), it is critical to identify the reservoir and intermediate hosts. The intermediate host can act as a biological bridge between the reservoir and humans. Despite active infection, the intermediate host may appear healthy or asymptomatic long enough for the virus to jump unnoticed to humans. The intermediate host offers the virus the additional advantage of a suitable environment for rapid evolution priming for the jump from animal species to humans. Postjump changes in the virus also tend to occur in the human host, and the significance of these changes is yet to be unraveled [29].

In addition to intermediate hosts, the reservoir is a key player in pathogen emergence. Fruit bats have been a common source

for a broad range of viruses associated with emerging human infections [30,31]. In the beginning of the 1990s, humans who came in close contact with the blood or body fluids of sick, infected horses (intermediate) acquired a new virus known as Hendra virus. Later, fruit bats were found to be the source for this paramyxovirus. Since then, Hendra virus has caused some isolated outbreaks of serious and often fatal infections in horses and humans [32]. Moreover, in a single outbreak in 1997, Menangle virus, another paramyxovirus circulating in bats, spilled over to pigs. Humans working in pig farms were directly exposed to the virus shed in the secretions of infected pigs, or indirectly through contaminated surfaces [33]. Fruit bats appear to harbor viruses with a broad range of hosts; viruses that utilize cellular receptors that are highly conserved across species have better chances of breaching species barrier [34,35]. For example, Nipah virus was a new human pathogen recognized in 1998 in association with pig farming and cases of fatal encephalitis. In addition to humans and pigs, the virus could naturally infect other species including horses, dogs, and cats [36]. Thus, these animals also became hosts for the virus. Although pigs were the intermediate host in the early outbreaks of Nipah in Malaysia and Singapore, more recent outbreaks in India and Bangladesh suggest direct transmission from bats to humans through contact with fruits contaminated with infectious bat fluids (eg, urine, saliva) [37]. Interestingly, numerous RNA viruses circulate in bats. RNA viruses are a predominant cause of newly emerging zoonotic diseases, such as Ebola and SARS-CoV-2. Accelerated rates of mutation and presence of several variants of a given strain provide RNA viruses with unmatched capacity for rapid adaptation in a short time [20].

Collectively, the above mentioned factors explain how activities pertaining to human-animal interaction pose an increasingly high risk of pathogen emergence. We may not have substantial evidence for the involvement of human-animal contact in the emergence of SARS-CoV-2, but the new outbreaks in mink farms in the Netherlands [38,39] certainly highlight how cross-species transmission could occur. Indeed, this possibly bidirectional spread between humans and animals necessitates policies that regulate human-animal contact. Furthermore, the expanding human population has led to more wildlife hunting, bush meat trade and consumption, live animal markets, densely populated livestock and poultry industries, exotic species trading, and rapid animal transportation to meet the growing demand for such products. This has created continuous and intense contact between humans and potential viral reservoirs, vectors, and intermediate hosts. Additionally, with increased human movement at exceptionally accelerated speed, pathogens can be introduced to previously uninfected areas, which are geographically distant from the source of infection, leading to disastrous pandemics across the globe. Given that we do not have a vaccine or immunity against most emerging viral diseases, resources directed at level 1 (ie, exposure) remain our best hope for preventing costly consequences. It is believed that emerging zoonotic diseases involve a complex interaction between multiple anthropogenic factors that modify the structure and dynamics of wildlife [40].

Recommendations

Recognizing the importance of these factors has led to intensive collaboration between different disciplines, including veterinary medicine, public health, environmental sciences, and social sciences, etc. This holistic approach, known as One Health, has shown promising results in curbing the spread of pathogens between humans and animals and between animals and animals [41]. For instance, the integration of veterinary sciences, epidemiology, and virology has led not only to the identification of the different animal reservoirs for rabies but also to the establishment of surveillance systems for monitoring outbreaks and the development of an effective vaccine [42]. These outcomes led to significant improvements in the control of rabies in both animals and humans. Similarly, a vaccine against Hendra virus helped control infection in horses and hence prevented transmission of the virus to humans [43]. Another example of fruitful multidisciplinary work is monitoring climate change to identify temperatures that favor pathogen transmission. For example, changes in climate, which in turn can affect mosquito movement, have been used in prediction models to monitor the emergence of West Nile virus [44].

Although in principle the One Health approach has been shown to be effective in controlling and preventing infectious diseases outbreaks, in reality, implementing it has proven to be challenging. Factors such as limited investments, lack of collaboration, and suboptimal surveillance systems have all hindered the achievement of optimal outcomes [45]. However, continuous progress in the One Health approach and supporting policies remain an essential shield in the face of future outbreaks [42]. This entails serious efforts to improve and implement:

1. Continuous surveillance of animals and vectors (eg, bats, rats, wild birds, primates, arthropods) for the emergence of new pathogens. This should help predict and prepare for the next pathogen threat and define regions susceptible to outbreaks and tools necessary to interrupt route of transmission. Additionally, further modeling, analyzing, and estimating the risk of emergence can help prepare suitable diagnostic tools for the rapid capture of a new outbreak, and frame essential mitigation protocols [46].

2. International cooperation to establish pathogen sequence libraries and databases updated with biological characterization of new pathogens. This can facilitate efforts in diagnosis, contact tracing, and potential vaccine development.
3. Studying and monitoring human behavior associated with increased risk of emerging diseases such as wildlife trade and bush meat consumption. Social sciences are important to help introduce behavioral modifications that can be beneficial and easily adhered to by communities. This also requires education and increase in public awareness to the dangers of high-risk behaviors.
4. Monitoring alterations in land use, climate change, and air quality, as well as introducing policies to reduce and/or mitigate ecological consequences [42]. Zoonosis is greatly impacted by changes in land use. These changes impact the natural habitat of wild animals and their biodiversity, influence their breeding sites, and determine the exposure rate of humans to pathogens in wild animals. Maintaining the biodiverse pool of wildlife and the natural habitat of wild animals should be a priority when planning landscapes [47].
5. Monitoring and implementing better, safer, and sustainable animal agricultural practices. Overcrowding, mixing of animals, overuse of antibiotics, and methods of transport are some of the drivers of pathogen emergence and re-emergence.

Conclusion

Humans share a close relationship with animals and their environment. Hence, the risk of emergence of new pathogens that can spill over into the human population cannot be completely eliminated. However, understanding the importance of the human-animal-ecosystem interface and tackling the diverse factors that influence the emergence of new pathogens are essential for better prevention, control, and mitigation. The One Health approach could have a significant positive impact in combatting the emergence of infectious diseases. However, this requires national and international cooperation, sharing of data, funding, implementation of policies and legislation, and political will.

Conflicts of Interest

None declared.

References

1. Chauhan S. Comprehensive review of coronavirus disease 2019 (COVID-19). *Biomed J* 2020 Jun 01 [FREE Full text] [doi: [10.1016/j.bj.2020.05.023](https://doi.org/10.1016/j.bj.2020.05.023)] [Medline: [32788071](https://pubmed.ncbi.nlm.nih.gov/32788071/)]
2. Harapan H, Itoh N, Yufika A, Winardi W, Keam S, Te H, et al. Coronavirus disease 2019 (COVID-19): A literature review. *J Infect Public Health* 2020 May;13(5):667-673 [FREE Full text] [doi: [10.1016/j.jiph.2020.03.019](https://doi.org/10.1016/j.jiph.2020.03.019)] [Medline: [32340833](https://pubmed.ncbi.nlm.nih.gov/32340833/)]
3. Lu R, Zhao X, Li J, Niu P, Yang B, Wu H, et al. Genomic characterisation and epidemiology of 2019 novel coronavirus: implications for virus origins and receptor binding. *Lancet* 2020 Feb 22;395(10224):565-574. [doi: [10.1016/S0140-6736\(20\)30251-8](https://doi.org/10.1016/S0140-6736(20)30251-8)] [Medline: [32007145](https://pubmed.ncbi.nlm.nih.gov/32007145/)]
4. Andersen KG, Rambaut A, Lipkin WI, Holmes EC, Garry RF. The proximal origin of SARS-CoV-2. *Nat Med* 2020 Apr 17;26(4):450-452 [FREE Full text] [doi: [10.1038/s41591-020-0820-9](https://doi.org/10.1038/s41591-020-0820-9)] [Medline: [32284615](https://pubmed.ncbi.nlm.nih.gov/32284615/)]

5. Lam TT, Jia N, Zhang Y, Shum MH, Jiang J, Zhu H, et al. Identifying SARS-CoV-2-related coronaviruses in Malayan pangolins. *Nature* 2020 Jul 26;583(7815):282-285. [doi: [10.1038/s41586-020-2169-0](https://doi.org/10.1038/s41586-020-2169-0)] [Medline: [32218527](https://pubmed.ncbi.nlm.nih.gov/32218527/)]
6. Choudhury A, Mukherjee S. In silico studies on the comparative characterization of the interactions of SARS-CoV-2 spike glycoprotein with ACE-2 receptor homologs and human TLRs. *J Med Virol* 2020 May 08. [doi: [10.1002/jmv.25987](https://doi.org/10.1002/jmv.25987)] [Medline: [32383269](https://pubmed.ncbi.nlm.nih.gov/32383269/)]
7. Qiu Y, Zhao Y, Wang Q, Li J, Zhou Z, Liao C, et al. Predicting the angiotensin converting enzyme 2 (ACE2) utilizing capability as the receptor of SARS-CoV-2. *Microbes Infect* 2020 May;22(4-5):221-225 [FREE Full text] [doi: [10.1016/j.micinf.2020.03.003](https://doi.org/10.1016/j.micinf.2020.03.003)] [Medline: [32199943](https://pubmed.ncbi.nlm.nih.gov/32199943/)]
8. Liu P, Jiang J, Wan X, Hua Y, Li L, Zhou J, et al. Are pangolins the intermediate host of the 2019 novel coronavirus (SARS-CoV-2)? *PLoS Pathog* 2020 May 14;16(5):e1008421 [FREE Full text] [doi: [10.1371/journal.ppat.1008421](https://doi.org/10.1371/journal.ppat.1008421)] [Medline: [32407364](https://pubmed.ncbi.nlm.nih.gov/32407364/)]
9. Shi J, Wen Z, Zhong G, Yang H, Wang C, Huang B, et al. Susceptibility of ferrets, cats, dogs, and other domesticated animals to SARS-coronavirus 2. *Science* 2020 May 29;368(6494):1016-1020 [FREE Full text] [doi: [10.1126/science.abb7015](https://doi.org/10.1126/science.abb7015)] [Medline: [32269068](https://pubmed.ncbi.nlm.nih.gov/32269068/)]
10. Schmitt CA, Bergey CM, Jasinska AJ, Ramensky V, Burt F, Svardal H, et al. ACE2 and TMPRSS2 variation in savanna monkeys (*Chlorocebus* spp.): Potential risk for zoonotic/anthroponotic transmission of SARS-CoV-2 and a potential model for functional studies. *PLoS One* 2020 Jun 23;15(6):e0235106 [FREE Full text] [doi: [10.1371/journal.pone.0235106](https://doi.org/10.1371/journal.pone.0235106)] [Medline: [32574196](https://pubmed.ncbi.nlm.nih.gov/32574196/)]
11. Zhai X, Sun J, Yan Z, Zhang J, Zhao J, Zhao Z, et al. Comparison of Severe Acute Respiratory Syndrome Coronavirus 2 Spike Protein Binding to ACE2 Receptors from Human, Pets, Farm Animals, and Putative Intermediate Hosts. *J Virol* 2020 Jul 16;94(15). [doi: [10.1128/jvi.00831-20](https://doi.org/10.1128/jvi.00831-20)]
12. Wassenaar T, Zou Y. 2019_nCoV/SARS-CoV-2: rapid classification of betacoronaviruses and identification of Traditional Chinese Medicine as potential origin of zoonotic coronaviruses. *Lett Appl Microbiol* 2020 May;70(5):342-348 [FREE Full text] [doi: [10.1111/lam.13285](https://doi.org/10.1111/lam.13285)] [Medline: [32060933](https://pubmed.ncbi.nlm.nih.gov/32060933/)]
13. Ji W, Wang W, Zhao X, Zai J, Li X. Cross-species transmission of the newly identified coronavirus 2019-nCoV. *J Med Virol* 2020 Feb 19;92(4):433-440. [doi: [10.1002/jmv.25682](https://doi.org/10.1002/jmv.25682)]
14. Lau SK, Luk HK, Wong AC, Li KS, Zhu L, He Z, et al. Possible Bat Origin of Severe Acute Respiratory Syndrome Coronavirus 2. *Emerg Infect Dis* 2020 Jul;26(7):1542-1547 [FREE Full text] [doi: [10.3201/eid2607.200092](https://doi.org/10.3201/eid2607.200092)] [Medline: [32315281](https://pubmed.ncbi.nlm.nih.gov/32315281/)]
15. Zhang Y, Holmes EC. A Genomic Perspective on the Origin and Emergence of SARS-CoV-2. *Cell* 2020 Apr;181(2):223-227. [doi: [10.1016/j.cell.2020.03.035](https://doi.org/10.1016/j.cell.2020.03.035)]
16. Li W, Zhang C, Sui J, Kuhn JH, Moore MJ, Luo S, et al. Receptor and viral determinants of SARS-coronavirus adaptation to human ACE2. *EMBO J* 2005 Apr 20;24(8):1634-1643 [FREE Full text] [doi: [10.1038/sj.emboj.7600640](https://doi.org/10.1038/sj.emboj.7600640)] [Medline: [15791205](https://pubmed.ncbi.nlm.nih.gov/15791205/)]
17. Chinese SARS Molecular Epidemiology Consortium. Molecular evolution of the SARS coronavirus during the course of the SARS epidemic in China. *Science* 2004 Mar 12;303(5664):1666-1669. [doi: [10.1126/science.1092002](https://doi.org/10.1126/science.1092002)] [Medline: [14752165](https://pubmed.ncbi.nlm.nih.gov/14752165/)]
18. Lloyd-Smith JO, George D, Pepin KM, Pitzer VE, Pulliam JRC, Dobson AP, et al. Epidemic dynamics at the human-animal interface. *Science* 2009 Dec 04;326(5958):1362-1367 [FREE Full text] [doi: [10.1126/science.1177345](https://doi.org/10.1126/science.1177345)] [Medline: [19965751](https://pubmed.ncbi.nlm.nih.gov/19965751/)]
19. Woolhouse M, Gaunt E. Ecological origins of novel human pathogens. *Crit Rev Microbiol* 2007 Oct 11;33(4):231-242. [doi: [10.1080/10408410701647560](https://doi.org/10.1080/10408410701647560)] [Medline: [18033594](https://pubmed.ncbi.nlm.nih.gov/18033594/)]
20. Domingo E. Rapid evolution of viral RNA genomes. *J Nutr* 1997 May;127(5 Suppl):958S-961S. [doi: [10.1093/jn/127.5.958S](https://doi.org/10.1093/jn/127.5.958S)] [Medline: [9164273](https://pubmed.ncbi.nlm.nih.gov/9164273/)]
21. Morse SS, Mazet JA, Woolhouse M, Parrish CR, Carroll D, Karesh WB, et al. Prediction and prevention of the next pandemic zoonosis. *The Lancet* 2012 Dec;380(9857):1956-1965. [doi: [10.1016/s0140-6736\(12\)61684-5](https://doi.org/10.1016/s0140-6736(12)61684-5)]
22. Woolhouse ME. Population biology of emerging and re-emerging pathogens. *Trends in Microbiology* 2002 Oct;10(10):s3-s7. [doi: [10.1016/s0966-842x\(02\)02428-9](https://doi.org/10.1016/s0966-842x(02)02428-9)]
23. Cleaveland S, Haydon D, Taylor L. Overviews of pathogen emergence: which pathogens emerge, when and why? *Curr Top Microbiol Immunol* 2007;315:85-111 [FREE Full text] [doi: [10.1007/978-3-540-70962-6_5](https://doi.org/10.1007/978-3-540-70962-6_5)] [Medline: [17848062](https://pubmed.ncbi.nlm.nih.gov/17848062/)]
24. Dietz K. The estimation of the basic reproduction number for infectious diseases. *Stat Methods Med Res* 1993 Jul 02;2(1):23-41. [doi: [10.1177/096228029300200103](https://doi.org/10.1177/096228029300200103)] [Medline: [8261248](https://pubmed.ncbi.nlm.nih.gov/8261248/)]
25. Wolfe ND, Dunavan CP, Diamond J. Origins of major human infectious diseases. *Nature* 2007 May 17;447(7142):279-283 [FREE Full text] [doi: [10.1038/nature05775](https://doi.org/10.1038/nature05775)] [Medline: [17507975](https://pubmed.ncbi.nlm.nih.gov/17507975/)]
26. Zhou P, Yang X, Wang X, Hu B, Zhang L, Zhang W, et al. A pneumonia outbreak associated with a new coronavirus of probable bat origin. *Nature* 2020 Feb 03;579(7798):270-273. [doi: [10.1038/s41586-020-2012-7](https://doi.org/10.1038/s41586-020-2012-7)]
27. Xiao K, Zhai J, Feng Y, Zhou N, Zhang X, Zou J, et al. Isolation of SARS-CoV-2-related coronavirus from Malayan pangolins. *Nature* 2020 May 7;583:286-289 [FREE Full text] [doi: [10.1038/s41586-020-2313-x](https://doi.org/10.1038/s41586-020-2313-x)]
28. Han G. Pangolins Harbor SARS-CoV-2-Related Coronaviruses. *Trends Microbiol* 2020 Jul;28(7):515-517 [FREE Full text] [doi: [10.1016/j.tim.2020.04.001](https://doi.org/10.1016/j.tim.2020.04.001)] [Medline: [32544437](https://pubmed.ncbi.nlm.nih.gov/32544437/)]

29. Grubaugh ND, Petrone ME, Holmes EC. We shouldn't worry when a virus mutates during disease outbreaks. *Nat Microbiol* 2020 Apr 18;5(4):529-530 [FREE Full text] [doi: [10.1038/s41564-020-0690-4](https://doi.org/10.1038/s41564-020-0690-4)] [Medline: [32071422](https://pubmed.ncbi.nlm.nih.gov/32071422/)]
30. Field HE. Bats and emerging zoonoses: henipaviruses and SARS. *Zoonoses Public Health* 2009 Aug;56(6-7):278-284. [doi: [10.1111/j.1863-2378.2008.01218.x](https://doi.org/10.1111/j.1863-2378.2008.01218.x)] [Medline: [19497090](https://pubmed.ncbi.nlm.nih.gov/19497090/)]
31. Letko M, Seifert SN, Olival KJ, Plowright RK, Munster VJ. Bat-borne virus diversity, spillover and emergence. *Nat Rev Microbiol* 2020 Aug 11;18(8):461-471 [FREE Full text] [doi: [10.1038/s41579-020-0394-z](https://doi.org/10.1038/s41579-020-0394-z)] [Medline: [32528128](https://pubmed.ncbi.nlm.nih.gov/32528128/)]
32. Field HE. Hendra virus ecology and transmission. *Curr Opin Virol* 2016 Feb;16:120-125. [doi: [10.1016/j.coviro.2016.02.004](https://doi.org/10.1016/j.coviro.2016.02.004)] [Medline: [26978066](https://pubmed.ncbi.nlm.nih.gov/26978066/)]
33. Bowden T, Bingham J, Harper J, Boyle D. Menangle virus, a pteropid bat paramyxovirus infectious for pigs and humans, exhibits tropism for secondary lymphoid organs and intestinal epithelium in weaned pigs. *J Gen Virol* 2012 May;93(Pt 5):1007-1016. [doi: [10.1099/vir.0.038448-0](https://doi.org/10.1099/vir.0.038448-0)] [Medline: [22278823](https://pubmed.ncbi.nlm.nih.gov/22278823/)]
34. Calisher CH, Childs JE, Field HE, Holmes KV, Schountz T. Bats: Important Reservoir Hosts of Emerging Viruses. *CMR* 2006 Jul;19(3):531-545. [doi: [10.1128/cmr.00017-06](https://doi.org/10.1128/cmr.00017-06)]
35. Yinda C, Ghogomu S, Conceição-Neto N, Beller L, Deboutte W, Vanhulle E, et al. Cameroonian fruit bats harbor divergent viruses, including rotavirus H, bastroviruses, and picobirnaviruses using an alternative genetic code. *Virus Evol* 2018 Jan;4(1):vey008 [FREE Full text] [doi: [10.1093/ve/vey008](https://doi.org/10.1093/ve/vey008)] [Medline: [29644096](https://pubmed.ncbi.nlm.nih.gov/29644096/)]
36. Chua K, Bellini W, Rota P, Harcourt B, Tamin A, Lam S, et al. Nipah virus: a recently emergent deadly paramyxovirus. *Science* 2000 May 26;288(5470):1432-1435. [doi: [10.1126/science.288.5470.1432](https://doi.org/10.1126/science.288.5470.1432)] [Medline: [10827955](https://pubmed.ncbi.nlm.nih.gov/10827955/)]
37. Ang BSP, Lim TCC, Wang L. Nipah Virus Infection. *J Clin Microbiol* 2018 May 25;56(6):e01875-17. [doi: [10.1128/jcm.01875-17](https://doi.org/10.1128/jcm.01875-17)]
38. Oreshkova N, Molenaar R, Vreman S, Harders F, Oude Munnink BB, Hakze-van der Honing RW, et al. SARS-CoV-2 infection in farmed minks, the Netherlands, April and May 2020. *Euro Surveill* 2020 Jun;25(23):25 [FREE Full text] [doi: [10.2807/1560-7917.ES.2020.25.23.2001005](https://doi.org/10.2807/1560-7917.ES.2020.25.23.2001005)] [Medline: [32553059](https://pubmed.ncbi.nlm.nih.gov/32553059/)]
39. Enserink M. Coronavirus rips through Dutch mink farms, triggering culls. *Science* 2020 Jun 12;368(6496):1169-1169. [doi: [10.1126/science.368.6496.1169](https://doi.org/10.1126/science.368.6496.1169)] [Medline: [32527808](https://pubmed.ncbi.nlm.nih.gov/32527808/)]
40. Daszak P, Cunningham A, Hyatt A. Anthropogenic environmental change and the emergence of infectious diseases in wildlife. *Acta Tropica* 2001 Feb;78(2):103-116. [doi: [10.1016/s0001-706x\(00\)00179-0](https://doi.org/10.1016/s0001-706x(00)00179-0)]
41. Gibbs EPJ. The evolution of One Health: a decade of progress and challenges for the future. *Vet Rec* 2014 Jan 25;174(4):85-91. [doi: [10.1136/vr.g143](https://doi.org/10.1136/vr.g143)] [Medline: [24464377](https://pubmed.ncbi.nlm.nih.gov/24464377/)]
42. Cunningham AA, Daszak P, Wood JLN. One Health, emerging infectious diseases and wildlife: two decades of progress? *Philos Trans R Soc Lond B Biol Sci* 2017 Jul 19;372(1725):20160167 [FREE Full text] [doi: [10.1098/rstb.2016.0167](https://doi.org/10.1098/rstb.2016.0167)] [Medline: [28584175](https://pubmed.ncbi.nlm.nih.gov/28584175/)]
43. Middleton D, Pallister J, Klein R, Feng Y, Haining J, Arkinstall R, et al. Hendra virus vaccine, a one health approach to protecting horse, human, and environmental health. *Emerg Infect Dis* 2014 Mar;20(3):372-379 [FREE Full text] [doi: [10.3201/eid2003.131159](https://doi.org/10.3201/eid2003.131159)] [Medline: [24572697](https://pubmed.ncbi.nlm.nih.gov/24572697/)]
44. Rabinowitz PM, Kock R, Kachani M, Kunkel R, Thomas J, Gilbert J, Stone Mountain One Health Proof of Concept Working Group. Toward proof of concept of a one health approach to disease prediction and control. *Emerg Infect Dis* 2013 Dec;19(12) [FREE Full text] [doi: [10.3201/eid1912.130265](https://doi.org/10.3201/eid1912.130265)] [Medline: [24295136](https://pubmed.ncbi.nlm.nih.gov/24295136/)]
45. Gebreyes WA, Dupouy-Camet J, Newport MJ, Oliveira CJB, Schlesinger LS, Saif YM, et al. The global one health paradigm: challenges and opportunities for tackling infectious diseases at the human, animal, and environment interface in low-resource settings. *PLoS Negl Trop Dis* 2014 Nov 13;8(11):e3257 [FREE Full text] [doi: [10.1371/journal.pntd.0003257](https://doi.org/10.1371/journal.pntd.0003257)] [Medline: [25393303](https://pubmed.ncbi.nlm.nih.gov/25393303/)]
46. Christaki E. New technologies in predicting, preventing and controlling emerging infectious diseases. *Virulence* 2015 Jun 11;6(6):558-565 [FREE Full text] [doi: [10.1080/21505594.2015.1040975](https://doi.org/10.1080/21505594.2015.1040975)] [Medline: [26068569](https://pubmed.ncbi.nlm.nih.gov/26068569/)]
47. Patz JA, Daszak P, Tabor GM, Aguirre AA, Pearl M, Epstein J, Working Group on Land Use ChangeDisease Emergence. Unhealthy landscapes: Policy recommendations on land use change and infectious disease emergence. *Environ Health Perspect* 2004 Jul;112(10):1092-1098. [doi: [10.1289/ehp.6877](https://doi.org/10.1289/ehp.6877)] [Medline: [15238283](https://pubmed.ncbi.nlm.nih.gov/15238283/)]

Abbreviations

- +ssRNA:** positive-sense, single-stranded RNA
- ACE2:** angiotensin-converting enzyme 2
- MERS-CoV:** Middle East respiratory syndrome coronavirus
- R₀:** reproduction number
- RNA:** ribonucleic acid
- S:** spike
- SARS:** severe acute respiratory syndrome
- SARS-CoV-1:** severe acute respiratory syndrome coronavirus

Edited by T Sanchez; submitted 03.07.20; peer-reviewed by S Dil, M Zinnah; comments to author 09.09.20; revised version received 17.09.20; accepted 18.09.20; published 07.10.20.

Please cite as:

Hassani A, Khan G

Human-Animal Interaction and the Emergence of SARS-CoV-2

JMIR Public Health Surveill 2020;6(4):e22117

URL: <http://publichealth.jmir.org/2020/4/e22117/>

doi: [10.2196/22117](https://doi.org/10.2196/22117)

PMID: [33001837](https://pubmed.ncbi.nlm.nih.gov/33001837/)

©Asma Hassani, Gulfaraz Khan. Originally published in JMIR Public Health and Surveillance (<http://publichealth.jmir.org>), 07.10.2020. This is an open-access article distributed under the terms of the Creative Commons Attribution License (<https://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in JMIR Public Health and Surveillance, is properly cited. The complete bibliographic information, a link to the original publication on <http://publichealth.jmir.org>, as well as this copyright and license information must be included.

Original Paper

Trends and Predictors of COVID-19 Information Sources and Their Relationship With Knowledge and Beliefs Related to the Pandemic: Nationwide Cross-Sectional Study

Shahmir H Ali¹, BA; Joshua Foreman^{1,2}, PhD; Yesim Tozan³, PhD; Ariadna Capasso¹, MFA; Abbey M Jones⁴, MPH; Ralph J DiClemente¹, PhD

¹Department of Social & Behavioral Sciences, School of Global Public Health, New York University, New York, NY, United States

²Ophthalmology, Department of Surgery, University of Melbourne, Melbourne, Australia

³Global Health Program, School of Global Public Health, New York University, New York, NY, United States

⁴Department of Epidemiology, School of Global Public Health, New York University, New York, NY, United States

Corresponding Author:

Ralph J DiClemente, PhD

Department of Social & Behavioral Sciences

School of Global Public Health

New York University

715 Broadway

New York, NY, 10003

United States

Phone: 1 (212) 992 3709

Email: rjd438@nyu.edu

Abstract

Background: During the COVID-19 pandemic, there is a heightened need to understand health information seeking behaviors to address disparities in knowledge and beliefs about the crisis.

Objective: This study assessed sociodemographic predictors of the use and trust of different COVID-19 information sources, as well as the association between information sources and knowledge and beliefs about the pandemic.

Methods: An online survey was conducted among US adults in two rounds during March and April 2020 using advertisement-based recruitment on social media. Participants were asked about their use of 11 different COVID-19 information sources as well as their most trusted source of information. The selection of COVID-related knowledge and belief questions was based on past empirical literature and salient concerns at the time of survey implementation.

Results: The sample consisted of 11,242 participants. When combined, traditional media sources (television, radio, podcasts, or newspapers) were the largest sources of COVID-19 information (91.2%). Among those using mainstream media sources for COVID-19 information (n=7811, 69.5%), popular outlets included CNN (24.0%), Fox News (19.3%), and other local or national networks (35.2%). The largest individual information source was government websites (87.6%). They were also the most trusted source of information (43.3%), although the odds of trusting government websites were lower among males (adjusted odds ratio [AOR] 0.58, 95% CI 0.53-0.63) and those aged 40-59 years and ≥60 years compared to those aged 18-39 years (AOR 0.83, 95% CI 0.74-0.92; AOR 0.62, 95% CI 0.54-0.71). Participants used an average of 6.1 sources (SD 2.3). Participants who were male, aged 40-59 years or ≥60 years; not working, unemployed, or retired; or Republican were likely to use fewer sources while those with children and higher educational attainment were likely to use more sources. Participants surveyed in April were markedly less likely to use (AOR 0.41, 95% CI 0.35-0.46) and trust (AOR 0.51, 95% CI 0.47-0.56) government sources. The association between information source and COVID-19 knowledge was mixed, while many COVID-19 beliefs were significantly predicted by information source; similar trends were observed with reliance on different types of mainstream media outlets.

Conclusions: COVID-19 information source was significantly determined by participant sociodemographic characteristics and was also associated with both knowledge and beliefs about the pandemic. Study findings can help inform COVID-19 health communication campaigns and highlight the impact of using a variety of different and trusted information sources.

(*JMIR Public Health Surveill* 2020;6(4):e21071) doi:[10.2196/21071](https://doi.org/10.2196/21071)

KEYWORDS

COVID-19; coronavirus; pandemic; outbreak; infectious disease; social media; information seeking behaviors; surveillance

Introduction

As of May 2020, the United States has experienced the most severe COVID-19 outbreak of any country in terms of confirmed numbers of cases and deaths [1]. The economic and social disruptions imposed by measures to contain the disease have been significant, with marked spikes in unemployment, poverty, and psychological suffering [2,3]. As such, authorities face the difficult task of convincing the public that compliance with these measures are justified and necessary to circumvent a potentially worse crisis. Therefore, the manner in which information is formulated, the channels through which it is disseminated, and the populations that are targeted must be considered when developing messaging and designing and implementing risk communication strategies.

In the current information age, there is an ever-growing multiplicity of available sources for health-related information, and the public has tended to shift in recent years from reliance on primarily mainstream news outlets toward other sources of information, including social media [4,5]. Sources of information vary in terms of their reliability, completeness, and verifiability, and in the context of the highly polarized political climate in the United States during an election year, antiscientific rhetoric and political bias may underpin reporting by many information outlets [6]. Of particular concern are social media and other online platforms that are not subject to peer review, fact-checking, or compliance with industry regulations to which mainstream sources are usually held [7]. For instance, an analysis of content on Twitter reported that one-quarter of tweets about COVID-19 contained misinformation [7]. During past infectious disease outbreaks, mainstream media sources such as television or newspaper outlets have been significant sources of information [8-11]. However, findings on the most trusted sources of information during such outbreaks have been mixed and have included health officials [8], television [8], the internet [12], and government [12].

During the rapid escalation of the COVID-19 pandemic in March and April 2020, we conducted an online survey on the sources of information used and trusted by US adults for acquiring COVID-19 information and ascertained how these sources varied according to key sociodemographic characteristics. Further, we assessed how differences in information sources were associated with variation in beliefs and levels of knowledge related to COVID-19.

Methods

Participant Recruitment

Details of the methods have been reported elsewhere [13]. Briefly, the sample was a self-selected nonprobability sample of social media users on Facebook and its affiliated platforms that was recruited through an on-platform advertisement campaign. Past research supports the use of Facebook as a valid, efficient, and cost-effective recruitment tool in health research

[14]. The advertisement campaign targeted adults aged ≥ 18 years of any sex residing in the United States. Advertisements with links to an anonymous web-based survey (Qualtrics) were placed on web- or mobile-based versions of Facebook, Messenger, Instagram, and the Facebook Audience Network (other mobile apps and websites partnered with Facebook). Participants were sampled in two rounds about one month apart, from March 20 to 30 and from April 16 to 21, 2020. To reduce redundant reporting, participants could only complete the survey once (based on IP address). Eligible participants for the current study included US residents aged ≥ 18 years (confirmed through two screening questions). Survey reporting followed the American Association for Public Opinion Research (AAPOR) guidelines [15]. The analytic sample for this study included those with information on any of the information source variables. The New York University Institutional Review Board reviewed and exempted the study procedures, and the need for explicit written or oral consent was also waived. Participation in the study was completely voluntary and did not involve compensation, monetary or otherwise.

Questionnaire

The survey was based on the Health Belief Model, which has been previously utilized in recent surveys on other viral outbreaks, such as H1N1 influenza [16], Middle East respiratory syndrome (MERS) [17], and Ebola [18,19]. The survey was also informed by the World Health Organization survey tool for behavioral insights on COVID-19 [20]. Sources of COVID-19-related information used by participants were measured in three ways. First, participants were asked whether or not they used any of the following sources to find information about COVID-19 (with a “not applicable” option): (1) spouse/partner, (2) other family members, (3) friends or coworkers, (4) religious leader, (5) doctor/medical provider, (6) television, (7) radio or podcasts, (8) newspaper (printed or online), (9) government or other official websites, (10) social media, and (11) Google search, Wikipedia, or other nongovernmental websites. Of the 11 variables provided, some were collapsed into categories based on shared characteristics across certain sources, with participants needing to have responded “yes” to using one or more of the listed information sources to be included in that category. The collapsed categories were the following: (1) traditional media (television, radio, podcasts, or newspapers), (2) online media (social media, Google search, Wikipedia, or other nongovernmental websites), (3) interpersonal sources (spouse/partner, other family members, and friends or coworkers). Participants were also asked if they used mainstream media sources of information for COVID-19; those who responded “yes” were asked which of the following mainstream media sources they received the most information from: (1) CNN, (2) Fox News, (3) MSNBC, (4) other local or national networks, or (5) other international networks. Second, a variable indicating the total number of sources used by each participant was created by summing the number of “yes” responses for each of the 11 information sources. Finally, participants were asked to identify the information source they

trusted the most. The full questionnaire utilized in this study has been published elsewhere [13].

Knowledge and awareness of the COVID-19 outbreak and protective practices were measured by 24 binary response format (True/False) items. Examples of knowledge questions included “Coronavirus is a contagious disease” and “How can you protect yourself from being infected with coronavirus?” with options including “Getting a flu shot” and “Wearing a face mask.” Responses were consistent with information provided by the Centers for Disease Control and Prevention (CDC) as of March and April of 2020. The accuracy of the information was first assessed in March and then reassessed in April, and no changes in information accuracy were identified in this time frame. Correct responses were summed to create a composite knowledge score. Items were adapted from surveys from previous epidemics [18,21,22] and updated to reflect knowledge relevant to COVID-19.

Beliefs about COVID-19 were measured using 6 four-point (Strongly Agree, Agree, Disagree, and Strongly Disagree) Likert scale items, which were then dichotomized into a binary Agree/Disagree variable. Items were adapted from previous surveys on infectious disease outbreaks, with consideration for salient COVID-19–related beliefs at the time (March 2020) [19]. In total, three of the belief questions concerned statements on the origin, spread, or severity of COVID-19 (eg, “Coronavirus is more deadly than the seasonal flu”), for which the data were still emerging at the time of the survey, while three other questions concerned beliefs regarding the coverage and significance of the COVID-19 outbreak (eg, “The amount of media attention devoted to coronavirus has been adequate”).

Demographic variables assessed included sex, race, age category, employment status, educational attainment, living with children <18 years of age, state of residence (recoded by US Census region), urban/rural residence, and political party affiliation. Since marital status and income were only assessed in the second round of the survey and thus were missing for approximately half (55%) of the study participants, these variables were not included in the regression analyses. Participants who selected “prefer not to say” for any questions were removed from analysis, with the exception of political affiliation due to the significant number of participants selecting this option (18.9%).

Statistical Analysis

Participant demographic characteristics were stratified by categories of information sources used. Multivariable logistic regression analyses were conducted to assess the effect of demographic determinants on the use and trust of COVID-19 information sources. Poisson regression was conducted to assess demographic determinants of the number of COVID-19 information sources given its appropriateness for modeling count data. Separate logistic regression models were conducted on the effect of time of survey (March versus April) on the use, trust, and total number of COVID-19 information sources, adjusted for demographic covariates. Of the 21 knowledge questions assessed during both rounds, 7 had a correct response rate below 90%. Logistic regression analysis was conducted on these seven questions and six COVID-19–related beliefs to assess the odds of a correct response (for knowledge questions) or of agreeing with the provided statement (for belief questions) according to the use, trust, and total number of information sources—each adjusted for the other information source variables, as well as all demographic covariates given their observed significance in health and health information seeking behaviors [23,24]. All tests were two-sided with a significance level of $P < .05$. Statistical analyses were performed using R (Version 4.0.0; R Foundation for Statistical Computing).

Results

Participant Characteristics

A total of 13,201 respondents were eligible to participate, of whom 12,908 commenced the survey; of these, 11,242 provided data on their sources of COVID-19 information. Due to the small sample size of participants who identified “Other” for sex ($n=8$), this category was unable to be analyzed and was removed for analysis. The sample size and proportion of participants who identified as races other than non-Hispanic White was small: Black, non-Hispanic ($n=66$, 0.6%), Asian Pacific Islander ($n=86$, 0.8%), Native American or American Indian ($n=87$, 0.8%); interracial, mixed race, or other ($n=259$, 2.5%); and Hispanic/Latinx ($n=267$, 2.6%). Therefore, in statistical analyses, participants were pooled into a singular category to enhance power in data analysis ($n=765$, 7.3%). Table 1 provides a summary of the participant characteristics.

Table 1. Characteristics of 11,242 participants with data on COVID-19 sources of information in online survey, March-April 2020^a.

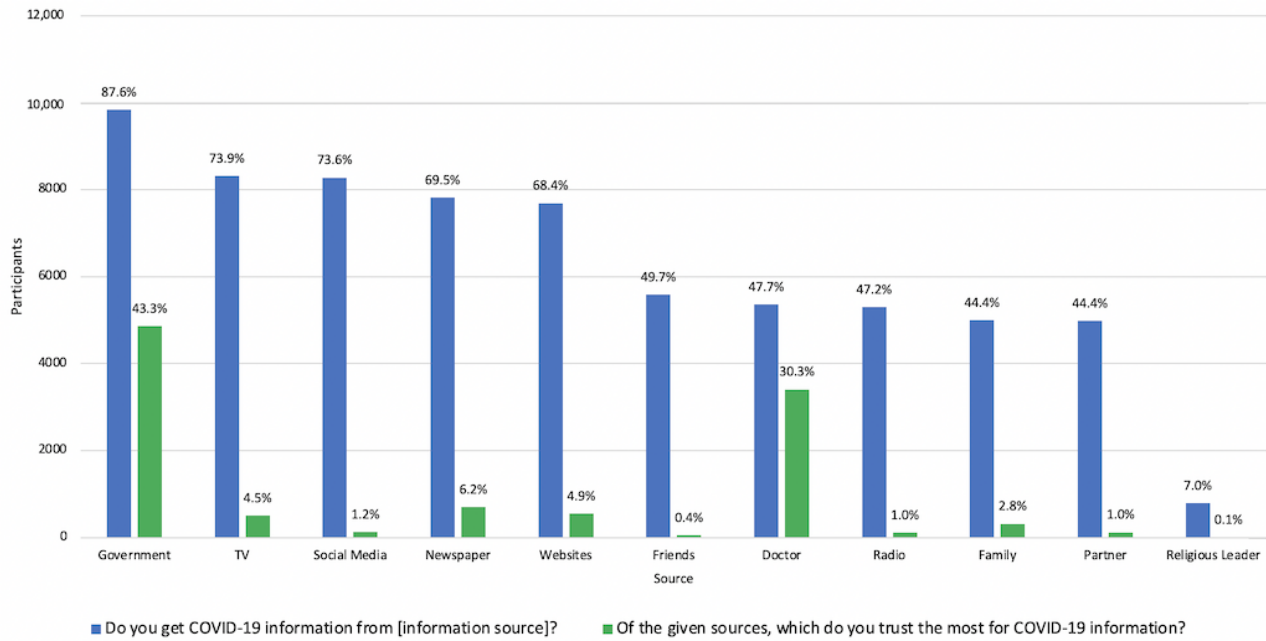
Characteristics	Source of information used						
	Total (n=11,242)	Traditional media (n=10,335)	Government (n=9845)	Online media (n=9653)	Interpersonal sources (n=7850)	Doctor (n=5361)	Religious leader (n=768)
Time of survey (%)							
March	5824 (51.8)	5409 (52.3)	5333 (54.2)	5100 (52.8)	4220 (53.8)	3010 (56.1)	500 (65.1)
April	5418 (48.2)	4926 (47.7)	4512 (45.8)	4553 (47.2)	3630 (46.2)	3196 (43.9)	268 (34.9)
Sex (%)							
Female	6566 (59.0)	6124 (59.8)	5920 (60.7)	5693 (59.5)	4648 (59.7)	3196 (60.1)	293 (61.5)
Male	4569 (41.0)	4117 (40.2)	3833 (39.3)	3868 (40.5)	3133 (40.3)	2121 (39.9)	293 (38.5)
Age (%)							
18-39 years old	2360 (21.0)	2160 (20.9)	2195 (22.3)	2064 (21.4)	1878 (23.9)	1133 (21.1)	164 (21.4)
40-59 years old	5061 (45.0)	4615 (44.7)	4479 (45.5)	4317 (44.7)	3534 (45.0)	2490 (46.4)	338 (44.0)
≥60 years old	3821 (34.0)	3560 (34.4)	3171 (32.2)	3272 (33.9)	2438 (31.1)	1738 (32.4)	266 (34.6)
Race (%)							
White, non-Hispanic	9648 (92.7)	8879 (92.7)	8449 (92.6)	8277 (92.8)	6723 (92.5)	4559 (91.6)	616 (90.9)
Non-White	765 (7.3)	701 (7.3)	678 (7.4)	646 (7.2)	545 (7.5)	416 (8.4)	62 (9.1)
Region (%)							
Northeast	2655 (26.4)	2481 (26.8)	2335 (26.4)	2282 (26.5)	1859 (26.4)	1242 (25.7)	132 (20.1)
Midwest	2797 (27.8)	2586 (27.9)	2448 (27.7)	2380 (27.6)	1972 (28.0)	1348 (27.9)	191 (29.0)
South	2852 (28.4)	2597 (28.0)	2513 (28.4)	2461 (28.5)	1982 (28.1)	1403 (29.0)	229 (34.8)
West	1746 (17.4)	1597 (17.2)	1544 (17.5)	1500 (17.4)	1241 (17.6)	840 (17.4)	106 (16.1)
Residence (%)							
Suburban	5126 (51.0)	4780 (51.6)	4548 (51.4)	4409 (51.1)	3622 (51.3)	2499 (51.7)	284 (43.2)
Urban	1624 (16.2)	1496 (16.2)	1424 (16.1)	1409 (16.3)	1145 (16.2)	786 (16.3)	90 (13.7)
Rural	3300 (32.8)	2985 (32.2)	2868 (32.4)	2805 (32.5)	2287 (32.4)	1548 (32.0)	284 (43.2)
Employment status (%)							
Employed	5980 (59.5)	5475 (59.1)	5373 (60.8)	5108 (59.2)	4397 (62.3)	2973 (61.5)	400 (60.8)
Student or unpaid work	615 (6.1)	575 (6.2)	570 (6.4)	530 (6.1)	469 (6.6)	277 (5.7)	45 (6.8)
Not working or unemployed	1200 (11.9)	1106 (11.9)	1043 (11.8)	1061 (12.3)	768 (10.9)	550 (11.4)	67 (10.2)
Retired	2255 (22.4)	2105 (22.7)	1854 (21.0)	1924 (22.3)	1420 (20.1)	1033 (21.4)	146 (22.2)
Children aged <18 years at home (%)							
No	7464 (71.7)	6891 (71.9)	6443 (70.6)	6379 (71.5)	5082 (69.9)	3517 (70.7)	451 (66.5)
Yes	2949 (28.3)	2689 (28.1)	2684 (29.4)	2544 (28.5)	2186 (30.1)	1458 (29.3)	227 (33.5)
Educational attainment (%)							
High school or lower	1299 (13.0)	1171 (12.7)	1100 (12.5)	1145 (13.3)	803 (11.4)	522 (10.8)	73 (11.1)
Some college or associate degree	3428 (34.2)	3107 (33.6)	2942 (33.4)	2910 (33.8)	2332 (33.1)	1623 (33.6)	214 (32.6)
Bachelor's degree or higher	5292 (52.8)	4957 (53.7)	4773 (54.1)	4544 (52.8)	3902 (55.4)	2679 (55.5)	370 (56.3)
Political affiliation (%)							
Democrat	3609 (36.0)	3493 (37.8)	3269 (37.1)	3160 (36.7)	2659 (37.8)	1870 (38.8)	165 (25.1)
Republican	2503 (25.0)	2227 (24.1)	2106 (23.9)	2134 (24.8)	1706 (24.2)	1084 (22.5)	256 (39.0)
Other	2009 (20.1)	1807 (19.6)	1769 (20.1)	1703 (19.8)	1374 (19.5)	970 (20.1)	94 (14.3)
Prefer not to say	1898 (18.9)	1708 (18.5)	1671 (19.0)	1602 (18.6)	1298 (18.4)	900 (18.7)	142 (21.6)

Characteristics	Source of information used						
	Total (n=11,242)	Traditional media (n=10,335)	Government (n=9845)	Online media (n=9653)	Interpersonal sources (n=7850)	Doctor (n=5361)	Religious leader (n=768)
Marital status (%)							
Married or cohabiting	3583 (70.9)	3269 (71.0)	3023 (71.6)	3001 (70.6)	2538 (74.3)	1616 (73.2)	185 (74.6)
Single	830 (16.4)	754 (16.4)	688 (16.3)	711 (16.7)	527 (15.4)	345 (15.6)	34 (13.7)
Divorced or separated	429 (8.5)	389 (8.4)	348 (8.2)	370 (8.7)	233 (6.8)	163 (7.4)	19 (7.7)
Widowed	213 (4.2)	195 (4.2)	166 (3.9)	171 (4.0)	118 (3.5)	85 (3.8)	10 (4.0)
Income (%)							
<\$30,000	577 (13.3)	515 (13.0)	462 (12.7)	487 (13.3)	330 (11.3)	228 (11.9)	32 (15.5)
\$30,000 to less than \$50,000	671 (15.5)	616 (15.6)	567 (15.5)	576 (15.8)	437 (15.0)	271 (14.2)	22 (14.0)
\$50,000 to less than \$75,000	767 (17.7)	687 (17.4)	618 (16.9)	636 (17.4)	484 (16.6)	331 (17.3)	46 (22.2)
\$75,000 to less than \$100,000	900 (20.8)	831 (21.0)	764 (20.9)	749 (20.5)	616 (21.2)	424 (22.1)	44 (21.3)
≥\$100,000	1418 (32.7)	1310 (33.1)	1237 (33.9)	1202 (32.9)	1044 (35.9)	661 (34.5)	56 (27.1)
Most trusted source (%)							
Government or other official websites	4867 (45.2)	4497 (45.4)	4673 (49.4)	4109 (44.4)	3297 (43.8)	2123 (41.2)	310 (42.9)
Television	509 (4.7)	503 (5.1)	362 (3.8)	458 (5.0)	330 (4.4)	132 (2.6)	22 (3.0)
Social media	131 (1.2)	105 (1.1)	81 (0.9)	126 (1.4)	82 (1.1)	29 (0.6)	10 (1.4)
Newspaper	699 (6.5)	691 (7.0)	599 (6.3)	636 (6.9)	523 (6.9)	270 (5.2)	35 (4.8)
Other web-based sources	549 (5.1)	459 (4.6)	423 (4.5)	527 (5.7)	345 (4.6)	152 (3.0)	22 (3.0)
Friends or coworkers	49 (0.5)	37 (0.4)	34 (0.4)	40 (0.4)	43 (0.6)	18 (0.3)	3 (0.4)
Doctor or medical provider	3408 (31.6)	3134 (31.6)	2909 (30.8)	2891 (31.3)	2444 (32.4)	2239 (43.5)	259 (35.9)
Radio or podcasts	115 (1.1)	114 (1.2)	81 (0.9)	101 (1.1)	75 (1.0)	39 (0.8)	12 (1.7)
Other family members	118 (1.1)	106 (1.1)	76 (0.8)	106 (1.1)	107 (1.4)	41 (0.8)	32 (1.4)
Spouse or partner	316 (2.9)	261 (2.6)	214 (2.3)	247 (2.7)	279 (3.7)	102 (2.0)	10 (4.4)
Religious leader	8 (0.1)	6 (0.1)	6 (0.1)	7 (0.1)	7 (0.1)	3 (0.1)	7 (1.0)

^aTotal number of responses with data on sources of information, excluding those selecting "not applicable" for all sources.

Geographic representation of participants included all US states. Overall, most participants were female (59.0%), non-Hispanic white (92.7%), employed (59.5%), and living in suburban environments (51.0%). [Figure 1](#) displays an overview of the information sources used and most trusted by the study population. Overall, traditional media was the most frequently utilized source of information (n=10,335, 91.2%); however, when all information sources were disaggregated from the synthesized categories, the largest individual source of

COVID-19 information was government websites (n=9845, 87.6%). Participants used an average of 6.1 sources (SD 2.3, range 0-11). Among those who used mainstream media sources for COVID-19 information (n=7811, 69.5%), other local or national networks were the most popular sources of COVID-19 information (35.2%), followed by CNN (24.0%), Fox News (19.3%), MSNBC (11.9%), and other international networks (5.3%).

Figure 1. Distribution of sources used and most trusted sources for information on COVID-19 (N=11,242).

Sociodemographic Factors Associated With Sources of COVID-19 Information

Males were significantly less likely than females to use all identified sources, excluding spouses/family/friends and religious leaders (Table 2). Participants aged 40-59 years and ≥ 60 years were less likely to use government websites compared to those aged 18-38 years (adjusted odds ratio [AOR] 0.59, 95% CI 0.47-0.71; AOR 0.47, 95% CI 0.37-0.60). Participants identifying as races other than non-Hispanic White were more likely to use doctors (AOR 1.39, 95% CI 1.18-1.64) and religious leaders (AOR 1.40, 95% CI 1.03-1.86) as a source of information. Those with a bachelor's degree or higher were more likely to use all of the sources, except traditional media.

Sociodemographic predictors of using mainstream media sources for COVID-19 information are displayed in Multimedia Appendix 1. Republicans were significantly more likely to rely upon Fox News (AOR 33.56, 95% CI 25.60-44.87), while they were less likely to rely on all other mainstream media sources. In contrast, those with a bachelor's degree or higher were more likely to rely on CNN (AOR 1.25, 95% CI 1.04-1.52) or other international networks (AOR 3.68, 95% CI 2.21-6.68) and less likely to rely on Fox News (AOR 0.72, 95% CI 0.61-0.87). Participants aged ≥ 60 years were more likely to rely on Fox News (AOR 1.41, 95% CI 1.12-1.77) and MSNBC (AOR 1.85, 95% CI 1.43-2.40) and less likely to rely on other international sources (AOR 0.67, 95% CI 0.47-0.95).

Table 2. Adjusted odds ratios (95% CI) of sociodemographic factors associated with COVID-19 information source (N=11,242)^a. Ref: Reference group.

Sociodemographic factors	Traditional media	Government	Online media	Interpersonal sources	Doctor	Religious leader
Sex						
Female	Ref	Ref	Ref	Ref	Ref	Ref
Male	0.74 (0.64-0.87) ^b	0.58 (0.51-0.66) ^b	0.88 (0.78-0.99) ^d	0.96 (0.88-1.06)	0.91 (0.84-0.99) ^d	0.89 (0.75-1.06)
Age						
18-39 years	Ref	Ref	Ref	Ref	Ref	Ref
40-59 years	0.99 (0.80-1.21)	0.58 (0.47-0.71) ^b	0.80 (0.68-0.94) ^c	0.61 (0.54-0.70) ^b	1.10 (0.96-1.23)	0.86 (0.69-1.08)
≥60 years	1.12 (0.85-1.46)	0.47 (0.37-0.60) ^b	0.91 (0.74-1.11)	0.52 (0.45-0.62) ^b	1.02 (0.88-1.17)	1.07 (0.81-1.42)
Race						
White	Ref	Ref	Ref	Ref	Ref	Ref
Non-White	0.96 (0.72-1.29)	0.95 (0.74-1.23)	0.87 (0.71-1.09)	1.02 (0.85-1.22)	1.39 (1.18-1.64) ^b	1.40 (1.03-1.86) ^d
Region						
Northeast	Ref	Ref	Ref	Ref	Ref	Ref
Midwest	0.88 (0.71-1.09)	0.95 (0.80-1.13)	0.94 (0.71-1.09)	0.98 (0.87-1.11)	1.07 (0.96-1.20)	1.30 (1.03-1.65) ^d
South	0.74 (0.60-0.92) ^c	1.09 (0.92-1.29)	1.06 (0.90-1.23)	0.97 (0.86-1.09)	1.10 (0.98-1.23)	1.50 (1.20-1.89) ^b
West	0.69 (0.55-0.88) ^c	1.07 (0.88-1.30)	1.00 (0.84-1.19)	1.03 (0.89-1.18)	1.04 (0.91-1.18)	1.28 (0.97-1.67)
Residence						
Suburban	Ref	Ref	Ref	Ref	Ref	Ref
Urban	0.81 (0.65-1.01)	0.95 (0.79-1.14)	1.05 (0.90-1.23)	1.02 (0.89-1.16)	1.00 (0.89-1.13)	1.28 (0.97-1.67)
Rural	0.80 (0.67-0.94) ^c	1.01 (0.88-1.17)	0.94 (0.83-1.25)	1.07 (0.96-1.18)	0.99 (0.90-1.09)	1.56 (1.31-1.86) ^b
Employment						
Employed	Ref	Ref	Ref	Ref	Ref	Ref
Student or unpaid	1.26 (0.89-1.83)	0.99 (0.71-1.39)	0.97 (0.76-1.25)	0.97 (0.79-1.20)	0.81 (0.68-0.97) ^d	1.05 (0.74-1.47)
Not working or unemployed	1.11 (0.87-1.42)	0.79 (0.65-0.96) ^d	1.30 (1.07-1.59) ^c	0.70 (0.61-0.80) ^b	0.87 (0.76-0.99) ^d	0.94 (0.71-1.23)
Retired	1.16 (0.91-1.48)	0.68 (0.57-0.82) ^b	0.96 (0.81-1.15)	0.78 (0.68-0.89) ^b	0.90 (0.79-1.03)	0.91 (0.71-1.16)
Children at home						
No	Ref	Ref	Ref	Ref	Ref	Ref
Yes	0.94 (0.78-1.12)	1.18 (1.00-1.39)	1.04 (0.91-1.19)	1.05 (0.94-1.17)	1.06 (0.96-1.17)	1.25 (1.03-1.51) ^d
Education						
High school or lower	Ref	Ref	Ref	Ref	Ref	Ref
Some college or associate degree	0.94 (0.74-1.17)	1.09 (0.90-1.31)	0.75 (0.62-0.91) ^c	1.28 (1.12-1.48) ^b	1.29 (1.13-1.48) ^b	1.21 (0.92-1.61)
Bachelor's degree or higher	1.23 (0.98-1.55)	1.49 (1.23-1.79) ^b	0.78 (0.64-0.94) ^d	1.62 (1.42-1.86) ^b	1.39 (1.22-1.59) ^b	1.56 (1.20-2.06) ^c
Political affiliation						
Democrat	Ref	Ref	Ref	Ref	Ref	Ref
Republican	0.30 (0.23-0.38) ^b	0.63 (0.53-0.74) ^b	0.86 (0.73-1.00)	0.83 (0.74-0.94) ^c	0.71 (0.64-0.80) ^b	2.24 (1.81-2.79) ^b
Other	0.32 (0.25-0.41) ^b	0.79 (0.66-0.96) ^d	0.80 (0.68-0.94) ^c	0.77 (0.67-0.87) ^b	0.90 (0.80-1.01)	1.03 (0.79-1.34)

Sociodemographic factors	Traditional media	Government	Online media	Interpersonal sources	Doctor	Religious leader
Prefer not to say	0.31 (0.24-0.40) ^b	0.80 (0.66-0.96) ^d	0.78 (0.66-0.92) ^c	0.83 (0.73-0.94) ^c	0.90 (0.80-1.01) ^c	1.71 (1.35-2.18) ^b

^aOdds of using source compared to those not using source, adjusting for all other covariates in tables.

^b $P < .001$.

^c $P < .01$.

^d $P < .05$.

With respect to predictors of the total number of COVID-19 sources used (not shown in tables), those using fewer sources included males compared to females ($\beta = -0.03$, 95% CI -0.04 to -0.01) and those aged 40-59 years and ≥ 60 years compared to those aged 18-39 years ($\beta = -0.05$, 95% CI -0.07 to -0.03 ; $\beta = -0.05$, 95% CI -0.08 to -0.03). Factors associated with increased number of sources included having children in the home compared to not having children in the home ($\beta = 0.03$, 95% CI 0.01-0.05), and having some college or a bachelor's degree or a higher level of educational attainment compared to those with a high school diploma or less educational attainment ($\beta = 0.03$, 95% CI 0.00-0.06; $\beta = 0.08$, 95% CI 0.05-0.10).

The most trusted information source was government websites (45.2%). The odds of trusting government websites were lower among males (AOR 0.58, 95% CI 0.53-0.63) and those aged 40-59 years and ≥ 60 years compared to those aged 18-38 years (AOR 0.83, 95% CI 0.74-0.92; AOR 0.62, 95% CI 0.54-0.71; data not shown in tables).

Overall, participants were significantly less likely to use any of the identified information sources in April compared to March (Multimedia Appendix 2); the adjusted odds of using government websites in April compared to March were particularly low (AOR 0.41, 95% CI 0.36-0.47). Similarly, compared to March, the odds of trusting government websites in April were significantly lower (AOR 0.51, 95% CI 0.47-0.56),

while the odds of trusting other websites, radios or podcasts, and spouses/partners more than doubling during that same time frame. In addition, participants in April used on average 0.58 fewer sources than those in March ($P < .001$).

The adjusted associations between COVID-19 information sources and knowledge of COVID-19 varied considerably by knowledge question (Table 3). An increase in the total number of information sources used was only associated with improved awareness that wearing a face mask was protective against COVID-19 infection (AOR 1.10, 95% CI 1.05-1.14). The use of some information sources, such as doctors and traditional media, were associated with improved knowledge for some questions but decreased knowledge for others. Overall, the use of government websites resulted in significantly better knowledge for 3 of the 7 examined questions, with the remaining 4 questions not significantly different between the groups.

The primary mainstream media source used for COVID-19 information was also significantly associated with knowledge about the pandemic (not shown in table). When adjusted for sociodemographic variables, total number of sources, and the most trusted source of information, those relying on CNN were more likely than those relying on other local/national media sources to correctly answer 2 of the 7 questions, while those relying on Fox News were more likely to incorrectly answer 3 of the 7 questions.

Table 3. Adjusted odds ratios (95% CI) of COVID-19 knowledge (correct answer) by information source (N=11,242)^a. Ref: Reference group.

Sources	Currently, there is an FDA-approved drug for treating individuals with the coronavirus.	Children are at high risk for complications from the coronavirus.	Alcohol-based hand sanitizers cannot protect you from the coronavirus.	The coronavirus originated from animals.	How can you protect against the coronavirus infection? Getting a flu shot.	How can you protect against the coronavirus infection? Wearing a face mask.	How can you protect against the coronavirus infection? Stop going to school/work.
Number of sources	1.03 (0.97-1.10)	1.03 (0.98-1.08)	1.04 (0.98-1.09)	0.96 (0.92-1.02)	0.97 (0.92-1.02)	1.10 (1.05-1.14) ^b	1.07 (1.00-1.14) ^d
Source group							
Traditional media	1.24 (0.95-1.61)	0.93 (0.72-1.19)	1.28 (1.00-1.63) ^d	0.78 (0.61-1.00) ^d	1.09 (0.83-1.40)	1.45 (1.18-1.77) ^b	1.93 (1.50-2.48) ^b
Government	1.30 (1.04-1.61) ^d	1.21 (0.99-1.46)	1.12 (0.91-1.36)	0.90 (0.73-1.10)	1.33 (1.08-1.62) ^c	0.88 (0.74-1.05)	1.44 (1.16-1.79) ^c
Online media	1.07 (0.85-1.35)	1.03 (0.84-1.25)	0.92 (0.74-1.13)	1.09 (0.89-1.34)	1.06 (0.86-1.30)	0.96 (0.82-1.13)	1.34 (1.06-1.68) ^d
Interpersonal sources	1.00 (0.81-1.22)	0.91 (0.77-1.08)	0.99 (0.83-1.18)	1.01 (0.85-1.20)	1.08 (0.91-1.29)	0.98 (0.85-1.12)	1.16 (0.94-1.42)
Doctor	0.91 (0.77-1.07)	0.82 (0.72-0.94) ^c	0.99 (0.86-1.15)	1.01 (0.87-1.16)	0.88 (0.76-1.02)	1.17 (1.05-1.31) ^c	1.09 (0.92-1.31)
Religious leader	0.65 (0.49-0.86) ^c	0.86 (0.68-1.10)	1.09 (0.83-1.44)	0.92 (0.69-1.21)	0.91 (0.71-1.17)	0.81 (0.67-0.99) ^d	1.02 (0.72-1.45)
Most trusted source^e							
Government	Ref	Ref	Ref	Ref	Ref	Ref	Ref
Television	0.54 (0.40-0.75) ^b	0.83 (0.63-1.09)	0.85 (0.64-1.14)	1.18 (0.88-1.55)	0.82 (0.62-1.09)	1.38 (1.08-1.79) ^d	0.81 (0.55-1.22)
Social media	0.43 (0.26-0.73) ^c	1.12 (0.65-2.07)	0.67 (0.41-1.17)	1.48 (0.85-2.46)	1.46 (0.78-3.04)	0.77 (0.49-1.23)	0.29 (0.17-0.49) ^b
Newspaper	1.40 (0.92-2.22)	1.11 (0.84-1.47)	1.32 (0.98-1.79)	0.76 (0.56-1.02)	1.17 (0.88-1.58)	0.97 (0.78-1.20)	0.98 (0.66-1.49)
Websites	0.54 (0.40-0.72) ^b	1.12 (0.84-1.53)	0.89 (0.67-1.18)	1.13 (0.84-1.49)	1.67 (1.18-2.42) ^c	0.67 (0.53-0.84) ^c	0.32 (0.24-0.42) ^b
Friends	0.41 (0.19-1.00) ^d	0.81 (0.37-2.06)	1.96 (0.70-8.20)	0.51 (0.12-1.44)	1.00 (0.42-2.97)	0.80 (0.40-1.66)	0.25 (0.11-0.56) ^b
Doctor	0.84 (0.71-1.00) ^d	0.88 (0.77-1.01)	0.97 (0.84-1.13)	1.03 (0.88-1.19)	0.81 (0.70-0.93) ^c	1.05 (0.94-1.18)	0.63 (0.52-0.75) ^b
Radio	0.42 (0.25-0.73) ^c	1.34 (0.73-2.72)	0.46 (0.28-0.77) ^c	2.19 (1.30-3.58) ^c	0.83 (0.48-1.56)	0.82 (0.51-1.37)	0.28 (0.17-0.47) ^b
Partner	0.60 (0.42-0.86) ^c	1.01 (0.72-1.46)	0.71 (0.50-1.01) ^d	1.42 (1.00-1.99) ^d	0.83 (0.59-1.21)	0.89 (0.66-1.20)	0.33 (0.23-0.47) ^b
Family	0.77 (0.42-1.54)	0.68 (0.41-1.19)	0.96 (0.55-1.81)	1.04 (0.55-1.83)	0.65 (0.38-1.14)	0.85 (0.53-1.40)	0.49 (0.27-0.95) ^d

^aAdjusted for all other information source variables in the model, as well as time of survey, sex, age, race, region, type of residence, working status, children, education, and political affiliation.

^b $P < .001$.

^c $P < .01$.

^d $P < .05$.

^eDue to the small sample size of those identifying religious leaders as their most trusted source (n=8), these were removed for analysis.

Changes in beliefs regarding COVID-19 were observed to be strongly and consistently associated with both the use of and trust in different information sources (Table 4). Compared to participants that did not use government websites, those who used government websites were more likely to disagree with the following statements: the coronavirus was released as an act of terrorism (AOR 0.64, 95% CI 0.54-0.76), the coronavirus is not as big a problem as the media suggests (AOR 0.65, 95%

CI 0.53-0.78), and warmer weather will reduce the spread of the coronavirus (AOR 0.69, 95% CI 0.58-0.80). Compared to those with the most trust in government websites, trust in most (≥ 6) of the other sources of information was associated with increased agreement that the coronavirus was released as an act of terrorism, disagreement that the coronavirus is deadlier than the flu, agreement that the coronavirus is not as big a problem as the media suggests, and disagreement that the amount of

media attention on the coronavirus has been adequate. Mainstream media source was also a significant determinant for COVID-19 beliefs (not shown in tables). Compared to those relying on other national/local media, those relying on CNN or MSNBC were more likely to agree that the coronavirus is deadlier than the seasonal flu, the amount of media attention devoted to the coronavirus has been adequate, and the coronavirus is a bigger problem than the government suggests. In addition, they were more likely to disagree that warmer weather will reduce the spread of the coronavirus and that the

coronavirus is not as big of a problem as the media suggests. Conversely, those relying on Fox News were more likely to agree that the coronavirus was released as an act of bioterrorism, warmer weather will reduce the spread of the coronavirus, and the coronavirus is not as big of a problem as the media suggests. In addition, they were more likely to disagree that the coronavirus is deadlier than the seasonal flu, the amount of media attention devoted to the coronavirus has been adequate, and the coronavirus is a bigger problem than the government suggests.

Table 4. Adjusted odds ratios (95% CI) of agreement of COVID-19 beliefs by information source, n=11,242^a. Ref: Reference group.

Sources	I think that the coronavirus was released as an act of bioterrorism.	The coronavirus is more deadly than the seasonal flu.	I think warmer weather will reduce the spread of the coronavirus.	The amount of media attention devoted to the coronavirus has been adequate.	The coronavirus is not as big of a problem as the media suggests.	The coronavirus is a bigger problem than the government suggests.
Number of sources	1.02 (0.97-1.06)	1.13 (1.08-1.19) ^b	1.02 (0.98-1.06)	1.13 (1.07-1.19) ^b	0.91 (0.86-0.95) ^b	1.08 (1.03-1.12) ^c
Source group						
Traditional media	0.51 (0.42-0.64) ^b	1.60 (1.29-1.98) ^b	0.76 (0.63-0.92) ^c	1.54 (1.24-1.19) ^b	0.47 (0.37-0.58) ^b	1.53 (1.24-1.89) ^b
Government	0.64 (0.54-0.76) ^b	1.48 (1.23-1.77) ^b	0.69 (0.58-0.80) ^b	1.10 (0.90-1.32)	0.65 (0.53-0.78) ^b	1.25 (1.05-1.48) ^d
Online media	0.98 (0.81-1.17)	1.09 (0.90-1.31)	1.07 (0.92-1.25)	1.05 (0.87-1.27)	1.05 (0.87-1.27)	1.03 (0.87-1.21)
Interpersonal sources	0.89 (0.76-1.04)	0.96 (0.82-1.13)	0.97 (0.85-1.11)	0.81 (0.69-0.96) ^d	0.90 (0.77-1.06)	0.95 (0.82-1.09)
Doctor	0.85 (0.75-0.96) ^d	1.02 (0.89-1.17)	0.84 (0.75-0.93) ^c	0.97 (0.85-1.12)	0.84 (0.73-0.96) ^c	1.24 (1.10-1.39) ^b
Religious leader	1.38 (1.11-1.70) ^c	0.78 (0.61-1.00) ^d	1.36 (1.12-1.64) ^c	0.74 (0.58-0.95) ^d	1.58 (1.25-1.99) ^b	0.57 (0.47-0.70) ^b
Most trusted source^e						
Government	Ref	Ref	Ref	Ref	Ref	Ref
Television	1.53 (1.19-1.97) ^c	0.96 (0.71-1.32)	0.95 (0.75-1.19)	1.55 (1.10-2.25) ^d	1.00 (0.74-1.43)	1.34 (1.04-1.74) ^d
Social media	2.52 (1.58-4.03) ^b	0.50 (0.31-0.81) ^d	1.99 (1.25-3.26) ^c	0.50 (0.32-0.81) ^c	2.46 (1.48-4.14) ^c	0.83 (0.51-1.35)
Newspaper	0.66 (0.48-0.90) ^c	1.07 (0.78-1.48)	0.89 (0.73-1.09)	1.67 (1.21-2.36) ^c	0.86 (0.63-1.15)	1.44 (1.13-1.84) ^c
Websites	2.08 (1.65-2.62) ^b	0.43 (0.34-0.55) ^b	1.37 (1.10-1.70) ^c	0.64 (0.50-0.82) ^b	2.27 (1.78-2.89) ^b	0.60 (0.48-0.76) ^b
Friends	3.01 (1.48-6.08) ^c	0.65 (0.30-1.49)	1.43 (0.73-2.86)	0.42 (0.21-0.88) ^d	2.58 (1.18-5.58) ^d	0.52 (0.24-1.07)
Doctor	1.45 (1.27-1.64) ^b	0.70 (0.61-0.81) ^b	1.07 (0.96-1.20)	0.82 (0.71-0.94) ^c	1.37 (1.20-1.57) ^b	0.97 (0.86-1.10)
Radio	1.55 (0.95-2.51)	0.37 (0.23-0.61) ^b	2.15 (1.34-3.53) ^c	0.72 (0.44-1.24)	3.16 (1.88-5.38) ^b	0.54 (0.32-0.88) ^d
Partner	2.82 (2.09-3.81) ^b	0.48 (0.36-0.66) ^b	1.73 (1.30-2.33) ^b	0.60 (0.45-0.82) ^c	2.07 (1.49-2.89) ^b	0.66 (0.48-0.89) ^c
Family	3.78 (2.36-6.11) ^b	0.59 (0.36-1.00) ^d	1.31 (0.83-2.07)	0.62 (0.37-1.05)	1.56 (0.92-2.59)	1.00 (0.62-1.63)

^aAdjusted for all other information source variables in the model, as well as time of survey, sex, age, race, region, type of residence, working status, children, education, political affiliation.

^b $P < .001$.

^c $P < .01$.

^d $P < .05$.

^eDue to the small sample size of those identifying religious leaders as their most trusted source (n=8), these were removed for analysis.

Discussion

Principal Findings

Overall, the choice of and trust in different COVID-19 information sources were observed to be significantly different across demographic variables, including sex, age, race, region, residence type, employment, education, and political affiliation. In addition, the type of source used and trust in each source were associated with different levels of knowledge and differences in beliefs regarding COVID-19. Despite advocacy by public health officials for the use of official or government sources of information (such as CDC or World Health Organization websites), only 45.2% of participants cited such sources as their most trusted sources of information, dropping from 53.3% in March to 36.8% in April. These findings suggest that public health professionals seeking to effectively communicate information on COVID-19 must acknowledge and appropriately adapt to disparities in public trust and information source preferences, particularly to address the differences in knowledge and beliefs regarding the pandemic.

Popular and Trusted Information Sources

The popularity of television and newspapers as sources of information during the current outbreak reflected past infectious disease outbreaks including the 2003 severe acute respiratory syndrome (SARS) outbreak [8], the 2009 H1N1 pandemic [9,10], and seasonal flu epidemics [11]. A qualitative study on communication during pandemics found that mainstream media (such as newspapers and television) were the most used source of information among participants despite being perceived as relatively untrustworthy [4], corroborating our study findings. However, while our study found government websites and doctors to be the most trusted sources, a study of the SARS outbreak in the Netherlands found that television and health officials were the most trusted sources of information [8], while a study of Ebola information in the United States found the internet and the government to be the most trusted information sources [12].

Findings that men were less likely to use almost all of the identified information sources, used fewer sources in general, and were also less likely to trust government websites for COVID-19 information suggest significant sex disparities in COVID-19 information source utilization. This evidence corresponds with other preliminary research observing that men are less likely to abide by advocated COVID-19 health behaviors [25], and that young men are more likely to agree with COVID-19 myths [26] and underscores the need for a sex-based targeted COVID-19 health information communication strategy. Moreover, age- and education-based disparities in COVID-19 knowledge and behaviors have also been observed in past research [27]. Given these disparities in COVID-19 information source usage, there is a clear need for targeted health communication campaigns to address these gaps. Lastly, disparities based on political affiliation also correspond with other evidence of its potential role in determining COVID-19 behaviors, including compliance with social distancing [28]. The use of specific mainstream media outlets was found to be significantly determined by political affiliation, sex, and age,

determinants which support past demographic analyses on mainstream media usage [29].

These findings suggest that trust in information sources may differ across time, place, culture, and type of disease outbreak, emphasizing the importance of updated surveillance on trends in information seeking behaviors during pandemics. For instance, the greater popularity of and trust in government sources may be explained by strong efforts by nongovernmental platforms such as Facebook, Google, and Twitter to promote official government websites [30]. Moreover, due to the small sample size of participants who identified as races other than non-Hispanic White, we were unable to conduct a comprehensive analysis on disaggregated racial and ethnic differences. However, past research has found immigrant communities from Asia have also been observed to display less confidence in their doctors and government agencies compared to other populations [31], suggesting a need for further intensive research on COVID-19 information source trends among minority communities in the United States, especially given their higher risk for morbidity and mortality from COVID-19 [32,33].

Likewise, unlike past research, the uniquely imminent and personal threat posed to members of the public responding to the survey should be considered. In other words, the Netherlands did not experience a SARS epidemic, nor did the United States experience an Ebola epidemic, and comparing perceptions regarding which information sources to consult and trust with these past case studies may differ depending on the level of perceived and actual risk within the population [34]. To meet the health communication needs of future pandemics or public health crises such as COVID-19, public health professionals and policy makers must conduct careful monitoring on up-to-date trends in information source usage to better target the delivery of public health information.

Importantly, findings also suggest that the likelihood of using different COVID-19 information sources changed between March and April. The finding that participants were less likely to trust sources such as government websites in this time frame has significant implications on the speed with which targeted public health information campaigns may need to be implemented to meet these rapid changes in information source utilization. Indeed, similar preliminary research has also observed a decline in trust of COVID-19 information provided by government sources [35]. Such evidence provides insight into how perceptions and utilization of information sources may significantly vary across different stages of a health crisis, supporting the need for continued, longitudinal public health surveillance to help the relevant authorities understand these trends and take action accordingly.

COVID-19 Knowledge and Information Sources

There have been concerns about the surge and spread of dangerous misinformation related to COVID-19 [36], including through online platforms like social media [37], particularly because there are many aspects of this novel disease that are presently poorly understood or subject to change as new evidence becomes available. Likewise, mainstream media sources have also garnered greater scrutiny over concerns that

COVID-19 misinformation is being perpetuated by certain media outlets [38], which was supported by the disparities in knowledge observed across those relying on different mainstream media sources. However, our findings also suggested that the use of and trust in information sources other than official government websites may not be associated with significantly different awareness of information about an emerging health crisis such as COVID-19. For instance, while social media has garnered increased attention due to its use as a platform to promulgate COVID-19 misinformation [37], the use of social media or web-based sources was in fact associated with increased awareness of one of the seven knowledge questions and had no effect on the other questions. Furthermore, those who trusted social media information the most (compared to government websites) only displayed reduced knowledge for two questions. Moreover, the sources from which members of the public obtain COVID-19 information may be interdependent; in previous influenza pandemics, doctors (who are a major source of health information) reported deriving much of their information from the internet and mass media [39,40]. These insights suggest that certain sources of information may not inherently result in compromised awareness of information pertaining to a health crisis, but other factors, such as the actual content, how the source is used by an individual, and the specific knowledge being assessed, may all play a relevant role in determining disparities in knowledge.

COVID-19 Beliefs and Information Source

Unlike with knowledge outcomes, the strong associations observed between both trust in and use of different information sources and COVID-19 beliefs suggest that different communication platforms are indeed having an impact on how the public subjectively perceives and interprets COVID-19 information. These associations were also observed in the reliance on different types of mainstream media sources, suggesting specific media outlets may also have a salient role in perpetuating certain beliefs about the pandemic. The perception that the coronavirus is deadlier than the flu was significantly higher among those who used and put the greatest trust in government websites, suggesting that these platforms have been able to effectively communicate the relative greater danger of COVID-19. Beliefs regarding communication of COVID-19 information displayed similar trends, with individuals trusting of different nongovernmental sources expressing greater agreement that the coronavirus is not as serious a problem as the media suggests, and disagreement that the coronavirus is a bigger problem than the government suggests. In a review on attitudes and beliefs during pandemics, various subjective understandings of the spread and significance of an infectious disease were directly associated with protective behaviors [41], suggesting that differing levels of seriousness

and perceived significance of a pandemic can have consequences for the collective public response.

Strengths and Limitations

This study was subject to a number of key limitations. First, the study sample was derived from nonprobability convenience sampling of Facebook and affiliated platform users, and although 70% of Americans use Facebook [5], certain demographic groups may be underrepresented (eg, racial, ethnic, and gender minorities), which is one component of why national representativeness cannot be assumed. Second, many of the information sources categorized are themselves inconsistent, such that within each source, the types and veracity of information vary markedly, and these disparities must be considered in interpreting the study findings. For example, given the wide variety of internet-based information sources, it is likely that many nonofficial or nongovernmental websites are providing valid, up-to-date information on COVID-19 and thus correlations between knowledge and beliefs about the pandemic may be significantly dependent on the specific internet sources being utilized rather than simply the platform itself, as observed in other health contexts [42]. Likewise, in recent years, other information source categories (such as social media) have significantly diversified (eg, web-based and app-based platforms, or those more video-based platforms such as TikTok), and this internal diversity may also influence trends in COVID-19 information source. Therefore, further research targeting more specific, stratified sources of information is warranted. Finally, given the emerging nature of the COVID-19 crisis, knowledge and salient beliefs are constantly evolving, and while the survey reflects a number of key questions relevant during March and April 2020, many of these may not be relevant in future months or years of the crisis. To address this, the survey used in the study will be adapted and reimplemented periodically over the course of the COVID crisis.

Conclusion

As the need to rapidly communicate information about the ongoing COVID-19 pandemic persists, our study findings provide key insights to policy makers seeking to understand what impact these information seeking behaviors are having on knowledge and beliefs regarding the outbreak. Likewise, information on the demographic profiles of who is using and trusting different information sources allows public health professionals to adapt communication strategies to reach a more diverse population. Future research should consider greater sampling of minority populations in the United States (notably racial and ethnic minorities, non-English speakers, and non-internet users) to provide further perspective on disparities in information seeking behaviors during COVID-19 and other health crises.

Conflicts of Interest

This study was self-funded by study authors, and the study authors declare no conflicts of interest, financial or otherwise.

Multimedia Appendix 1

Sociodemographic factors associated with mainstream media sources of COVID-19 information.

[[DOCX File , 18 KB - publichealth_v6i4e21071_app1.docx](#)]

Multimedia Appendix 2

Changes in COVID-19 information source between March and April 2020.

[[DOCX File , 15 KB - publichealth_v6i4e21071_app2.docx](#)]

References

1. Dong E, Du H, Gardner L. An interactive web-based dashboard to track COVID-19 in real time. *The Lancet Infectious Diseases* 2020 May;20(5):533-534. [doi: [10.1016/s1473-3099\(20\)30120-1](#)]
2. Panchal N, Kamal R, Orgera K, Cox C, Garfield R, Hamel L, et al. The Implications of COVID-19 for Mental Health and Substance Use. Kaiser Family Foundation. 2020. URL: <https://www.kff.org/health-reform/issue-brief/the-implications-of-covid-19-for-mental-health-and-substance-use/> [accessed 2020-05-11]
3. Parolin Z, Wimer C. Forecasting Estimates of Poverty during the COVID-19 Crisis. 2020. URL: <https://ideas.repec.org/p/aji/briefs/2046.html> [accessed 2020-09-29]
4. Henrich N, Holmes B. Communicating during a pandemic: information the public wants about the disease and new vaccines and drugs. *Health Promot Pract* 2011 Jul 08;12(4):610-619. [doi: [10.1177/1524839910363536](#)] [Medline: [21059872](#)]
5. Perrin A, Anderson M. Share of US adults using social media, including Facebook, is mostly unchanged since 2018. Pew Research Center. 2019. URL: <https://www.pewresearch.org/fact-tank/2019/04/10/share-of-u-s-adults-using-social-media-including-facebook-is-mostly-unchanged-since-2018/> [accessed 2020-05-23]
6. Frenkel S, Alba D, Zhong R. Surge of Virus Misinformation Stumps Facebook and Twitter. *The New York Times*. 2020. URL: <https://www.nytimes.com/2020/03/08/technology/coronavirus-misinformation-social-media.html> [accessed 2020-04-04]
7. Kouzy R, Abi Jaoude J, Kraitem A, El Alam MB, Karam B, Adib E, et al. Coronavirus Goes Viral: Quantifying the COVID-19 Misinformation Epidemic on Twitter. *Cureus* 2020 Mar 13;12(3):e7255 [FREE Full text] [doi: [10.7759/cureus.7255](#)] [Medline: [32292669](#)]
8. Brug J, Aro AR, Oenema A, de Zwart O, Richardus JH, Bishop GD. SARS risk perception, knowledge, precautions, and information sources, the Netherlands. *Emerg Infect Dis* 2004 Aug;10(8):1486-1489 [FREE Full text] [doi: [10.3201/eid1008.040283](#)] [Medline: [15496256](#)]
9. Wong LP, Sam I. Public sources of information and information needs for pandemic influenza A(H1N1). *J Community Health* 2010 Dec 22;35(6):676-682. [doi: [10.1007/s10900-010-9271-4](#)] [Medline: [20411411](#)]
10. Walter D, Bohmer M, Reiter S, Krause G, Wichmann O. Risk perception and information-seeking behaviour during the 2009/10 influenza A(H1N1)pdm09 pandemic in Germany. *Euro Surveill* 2012 Mar 29;17(13) [FREE Full text] [Medline: [22490383](#)]
11. Gargano LM, Underwood NL, Sales JM, Seib K, Morfaw C, Murray D, et al. Influence of sources of information about influenza vaccine on parental attitudes and adolescent vaccine receipt. *Hum Vaccin Immunother* 2015 May 21;11(7):1641-1647 [FREE Full text] [doi: [10.1080/21645515.2015.1038445](#)] [Medline: [25996686](#)]
12. Rolison JJ, Hanoch Y. Knowledge and risk perceptions of the Ebola virus in the United States. *Prev Med Rep* 2015;2:262-264 [FREE Full text] [doi: [10.1016/j.pmedr.2015.04.005](#)] [Medline: [26844081](#)]
13. Ali SH, Foreman J, Capasso A, Jones AM, Tozan Y, DiClemente RJ. Social media as a recruitment platform for a nationwide online survey of COVID-19 knowledge, beliefs, and practices in the United States: methodology and feasibility analysis. *BMC Med Res Methodol* 2020 May 13;20(1):116 [FREE Full text] [doi: [10.1186/s12874-020-01011-0](#)] [Medline: [32404050](#)]
14. Whitaker C, Stevelink S, Fear N. The Use of Facebook in Recruiting Participants for Health Research Purposes: A Systematic Review. *J Med Internet Res* 2017 Aug 28;19(8):e290 [FREE Full text] [doi: [10.2196/jmir.7071](#)] [Medline: [28851679](#)]
15. The American Association for Public Opinion Research. Standard Definitions: Final Dispositions of Case Codes and Outcome Rates for Surveys. 2016. URL: https://www.aapor.org/AAPOR_Main/media/publications/Standard-Definitions20169theditionfinal.pdf [accessed 2020-09-29]
16. Hasan F, Khan M, Ali M. Swine Flu: Knowledge, Attitude, and Practices Survey of Medical and Dental Students of Karachi. *Cureus* 2018 Jan 09;10(1):e2048-e2048 [FREE Full text] [doi: [10.7759/cureus.2048](#)] [Medline: [29541569](#)]
17. Al-Rabiaah A, Temsah M, Al-Eyadhy AA, Hasan GM, Al-Zamil F, Al-Subaie S, et al. Middle East Respiratory Syndrome-Corona Virus (MERS-CoV) associated stress among medical students at a university teaching hospital in Saudi Arabia. *J Infect Public Health* 2020 May;13(5):687-691 [FREE Full text] [doi: [10.1016/j.jiph.2020.01.005](#)] [Medline: [32001194](#)]
18. Painter JE, DiClemente RJ, von Fricken ME. Interest in an Ebola vaccine among a U.S. national sample during the height of the 2014-2016 Ebola outbreak in West Africa. *Vaccine* 2017 Jan 23;35(4):508-512. [doi: [10.1016/j.vaccine.2016.11.093](#)] [Medline: [28040206](#)]
19. Painter J, von Fricken ME, Viana de O Mesquita S, DiClemente R. Willingness to pay for an Ebola vaccine during the 2014-2016 ebola outbreak in West Africa: Results from a U.S. National sample. *Hum Vaccin Immunother* 2018 Jul 03;14(7):1665-1671 [FREE Full text] [doi: [10.1080/21645515.2018.1423928](#)] [Medline: [29333950](#)]

20. World Health Organization. Survey Tool and Guidance: Rapid, simple, flexible behavioural insights on COVID-19. Geneva: World Health Organization; 2020. URL: <https://apps.who.int/iris/handle/10665/333549> [accessed 2020-09-29]
21. Jalloh MF, Li W, Bunnell RE, Ethier KA, O'Leary A, Hageman KM, et al. Impact of Ebola experiences and risk perceptions on mental health in Sierra Leone, July 2015. *BMJ Glob Health* 2018 Mar 17;3(2):e000471. [doi: [10.1136/bmjgh-2017-000471](https://doi.org/10.1136/bmjgh-2017-000471)] [Medline: [29607096](https://pubmed.ncbi.nlm.nih.gov/29607096/)]
22. Lau JT, Kim JH, Tsui H, Griffiths S. Perceptions related to human avian influenza and their associations with anticipated psychological and behavioral responses at the onset of outbreak in the Hong Kong Chinese general population. *Am J Infect Control* 2007 Feb;35(1):38-49 [FREE Full text] [doi: [10.1016/j.ajic.2006.07.010](https://doi.org/10.1016/j.ajic.2006.07.010)] [Medline: [17276790](https://pubmed.ncbi.nlm.nih.gov/17276790/)]
23. Agency for Healthcare Research and Quality. 2017 National healthcare quality and disparities report (AHRQ Publication No. 18-0033-EF). 2018. URL: <https://www.ahrq.gov/sites/default/files/wysiwyg/research/findings/nhqdr/2017nhqdr.pdf> [accessed 2020-09-29]
24. Somera LP, Lee H, Badowski G, Cassel K. Health Information Seeking, Source Trust, and Culture: A Comparative Analysis of Health Information Trends and Needs Between Guam and the United States. *J Health Commun* 2016 Mar 16;21(4):469-478 [FREE Full text] [doi: [10.1080/10810730.2015.1095822](https://doi.org/10.1080/10810730.2015.1095822)] [Medline: [26983674](https://pubmed.ncbi.nlm.nih.gov/26983674/)]
25. Clark C, Davila A, Regis M, Kraus S. Predictors of COVID-19 voluntary compliance behaviors: An international investigation. *Glob Transit* 2020;2:76-82 [FREE Full text] [doi: [10.1016/j.glt.2020.06.003](https://doi.org/10.1016/j.glt.2020.06.003)] [Medline: [32835202](https://pubmed.ncbi.nlm.nih.gov/32835202/)]
26. Pickles K, Cvejic E, Nicel B. COVID-19: Beliefs in misinformation in the Australian community. medRxiv (preprint) 2020 Aug 06 [FREE Full text] [doi: [10.1101/2020.08.04.20168583](https://doi.org/10.1101/2020.08.04.20168583)]
27. Clements JM. Knowledge and Behaviors Toward COVID-19 Among US Residents During the Early Days of the Pandemic: Cross-Sectional Online Questionnaire. *JMIR Public Health Surveill* 2020 May 08;6(2):e19161 [FREE Full text] [doi: [10.2196/19161](https://doi.org/10.2196/19161)] [Medline: [32369759](https://pubmed.ncbi.nlm.nih.gov/32369759/)]
28. Painter M, Qiu T. Political Beliefs affect Compliance with COVID-19 Social Distancing Orders. *SSRN Journal* 2020 Jul 03 [FREE Full text] [doi: [10.2139/ssrn.3569098](https://doi.org/10.2139/ssrn.3569098)]
29. Who's watching? A look at the demographics of cable news channel watchers. *Public Opinion Strategies*. 2019. URL: <https://pos.org/whos-watching-a-look-at-the-demographics-of-cable-news-channel-watchers/> [accessed 2020-08-17]
30. Romm T. Facebook, Google and Twitter scramble to stop misinformation about coronavirus. *The Washington Post*. 2020 Jan 27. URL: <https://www.washingtonpost.com/technology/2020/01/27/facebook-google-twitter-scramble-stop-misinformation-about-coronavirus/> [accessed 2020-04-29]
31. Voeten HACM, de Zwart O, Veldhuijzen IK, Yuen C, Jiang X, Elam G, et al. Sources of information and health beliefs related to SARS and avian influenza among Chinese communities in the United Kingdom and The Netherlands, compared to the general population in these countries. *Int J Behav Med* 2009 Jan 29;16(1):49-57 [FREE Full text] [doi: [10.1007/s12529-008-9006-4](https://doi.org/10.1007/s12529-008-9006-4)] [Medline: [19184453](https://pubmed.ncbi.nlm.nih.gov/19184453/)]
32. Centers for Disease Control and Prevention. Health Equity Considerations and Racial and Ethnic Minority Groups. 2020 Jul 24. URL: <https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/racial-ethnic-minorities.html> [accessed 2020-05-08]
33. Wortham J, Lee J, Althomsons S, Latash J, Davidson A, Guerra K, et al. Characteristics of Persons Who Died with COVID-19 - United States, February 12-May 18, 2020. *MMWR Morb Mortal Wkly Rep* 2020 Jul 17;69(28):923-929 [FREE Full text] [doi: [10.15585/mmwr.mm6928e1](https://doi.org/10.15585/mmwr.mm6928e1)] [Medline: [32673298](https://pubmed.ncbi.nlm.nih.gov/32673298/)]
34. Sadique MZ, Edmunds WJ, Smith RD, Meerding WJ, de Zwart O, Brug J, et al. Precautionary behavior in response to perceived threat of pandemic influenza. *Emerg Infect Dis* 2007 Sep;13(9):1307-1313 [FREE Full text] [doi: [10.3201/eid1309.070372](https://doi.org/10.3201/eid1309.070372)] [Medline: [18252100](https://pubmed.ncbi.nlm.nih.gov/18252100/)]
35. Boyl J, Brassel T, Dayton J. American trust in COVID-19 information from federal and state/local government is trending downward. *ICF International*. 2020 Jun 04. URL: <https://www.icf.com/insights/health/covid-19-survey-trust-government-response-erodes> [accessed 2020-08-17]
36. Mian A, Khan S. Coronavirus: the spread of misinformation. *BMC Med* 2020 Mar 18;18(1):89 [FREE Full text] [doi: [10.1186/s12916-020-01556-3](https://doi.org/10.1186/s12916-020-01556-3)] [Medline: [32188445](https://pubmed.ncbi.nlm.nih.gov/32188445/)]
37. Pennycook G, McPhetres J, Zhang Y, Lu JG, Rand DG. Fighting COVID-19 Misinformation on Social Media: Experimental Evidence for a Scalable Accuracy-Nudge Intervention. *Psychol Sci* 2020 Jul;31(7):770-780. [doi: [10.1177/0956797620939054](https://doi.org/10.1177/0956797620939054)] [Medline: [32603243](https://pubmed.ncbi.nlm.nih.gov/32603243/)]
38. Ingraham C. New research explores how conservative media misinformation may have intensified the severity of the pandemic. *The Washington Post*. 2020 Jun 25. URL: <https://www.washingtonpost.com/business/2020/06/25/fox-news-hannity-coronavirus-misinformation/> [accessed 2020-08-17]
39. La Torre G, Semyonov L, Mannocci A, Boccia A. Knowledge, attitude, and behaviour of public health doctors towards pandemic influenza compared to the general population in Italy. *Scand J Public Health* 2012 Feb 17;40(1):69-75. [doi: [10.1177/1403494811424612](https://doi.org/10.1177/1403494811424612)] [Medline: [22006167](https://pubmed.ncbi.nlm.nih.gov/22006167/)]
40. Gholami J, Hosseini SH, Ashoorkhani M, Majdzadeh R. Lessons Learned from H1N1 Epidemic: The Role of Mass Media in Informing Physicians. *Int J Prev Med* 2011 Jan;2(1):32-37 [FREE Full text] [Medline: [21448403](https://pubmed.ncbi.nlm.nih.gov/21448403/)]
41. Bish A, Michie S. Demographic and attitudinal determinants of protective behaviours during a pandemic: a review. *Br J Health Psychol* 2010 Nov;15(Pt 4):797-824 [FREE Full text] [doi: [10.1348/135910710X485826](https://doi.org/10.1348/135910710X485826)] [Medline: [20109274](https://pubmed.ncbi.nlm.nih.gov/20109274/)]

42. Fisher JH, O'Connor D, Flexman AM, Shapera S, Ryerson CJ. Accuracy and Reliability of Internet Resources for Information on Idiopathic Pulmonary Fibrosis. *Am J Respir Crit Care Med* 2016 Jul 15;194(2):218-225. [doi: [10.1164/rccm.201512-2393oc](https://doi.org/10.1164/rccm.201512-2393oc)]

Abbreviations

CDC: Centers for Disease Control and Prevention

Edited by T Sanchez; submitted 04.06.20; peer-reviewed by M Prietula, JM Chen, M Waring; comments to author 13.08.20; revised version received 20.08.20; accepted 09.09.20; published 08.10.20.

Please cite as:

Ali SH, Foreman J, Tozan Y, Capasso A, Jones AM, DiClemente RJ

Trends and Predictors of COVID-19 Information Sources and Their Relationship With Knowledge and Beliefs Related to the Pandemic: Nationwide Cross-Sectional Study

JMIR Public Health Surveill 2020;6(4):e21071

URL: <http://publichealth.jmir.org/2020/4/e21071/>

doi: [10.2196/21071](https://doi.org/10.2196/21071)

PMID: [32936775](https://pubmed.ncbi.nlm.nih.gov/32936775/)

©Shahmir H Ali, Joshua Foreman, Yesim Tozan, Ariadna Capasso, Abbey M Jones, Ralph J DiClemente. Originally published in *JMIR Public Health and Surveillance* (<http://publichealth.jmir.org>), 08.10.2020. This is an open-access article distributed under the terms of the Creative Commons Attribution License (<https://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in *JMIR Public Health and Surveillance*, is properly cited. The complete bibliographic information, a link to the original publication on <http://publichealth.jmir.org>, as well as this copyright and license information must be included.

Original Paper

Novel Approach to Support Rapid Data Collection, Management, and Visualization During the COVID-19 Outbreak Response in the World Health Organization African Region: Development of a Data Summarization and Visualization Tool

Kamran Ahmed¹, MS, MD, FPHI; Muhammad Arish Bukhari¹, MIS; Tamayi Mlanda¹, MSc; Jean Paul Kimenyi¹, MSc; Polly Wallace², MSc; Charles Okot Lukoya¹, MPH; Esther L Hamblion¹, MSc, PhD; Benido Impouma¹, MSc, MD

¹Regional Office for Africa, World Health Organization, Brazzaville, Congo

²Australian National University, Canberra, Australia

Corresponding Author:

Kamran Ahmed, MS, MD, FPHI

Regional Office for Africa

World Health Organization

Cite du Djoue, PO Box 06

Brazzaville

Congo

Phone: 242 770 02 02

Email: drkamranrajput@gmail.com

Abstract

Background: The COVID-19 pandemic has created unprecedented challenges to the systematic and timely sharing of COVID-19 field data collection and management. The World Health Organization (WHO) is working with health partners on the rollout and implementation of a robust electronic field data collection platform. The delay in the deployment and rollout of this electronic platform in the WHO African Region, as a consequence of the application of large-scale public health and social measures including movement restrictions and geographical area quarantine, left a gap between data collection and management. This led to the need to develop interim data management solutions to accurately monitor the evolution of the pandemic and support the deployment of appropriate public health interventions.

Objective: The aim of this study is to review the design, development, and implementation of the COVID-19 Data Summarization and Visualization (DSV) tool as a rapidly deployable solution to fill this critical data collection gap as an interim solution.

Methods: This paper reviews the processes undertaken to research and develop a tool to bridge the data collection gap between the onset of a COVID-19 outbreak and the start of data collection using a prioritized electronic platform such as Go.Data in the WHO African Region.

Results: In anticipation of the implementation of a prioritized tool for field data collection, the DSV tool was deployed in 18 member states for COVID-19 outbreak data management. We highlight preliminary findings and lessons learned from the DSV tool deployment in the WHO African Region.

Conclusions: We developed a rapidly deployable tool for COVID-19 data collection and visualization in the WHO African Region. The lessons drawn on this experience offer an opportunity to learn and apply these to improve future similar public health informatics initiatives in an outbreak or similar humanitarian setting, particularly in low- and middle-income countries.

(*JMIR Public Health Surveill* 2020;6(4):e20355) doi:[10.2196/20355](https://doi.org/10.2196/20355)

KEYWORDS

COVID-19; health information management; data collection; visualization; EWARS; WHO African region; Go.Data; outbreak; pandemic; health emergencies

Introduction

In December 2019, a cluster of cases emerged in China caused by a novel coronavirus disease, officially named COVID-19 by the World Health Organization (WHO) [1]. Since, COVID-19 has spread widely with a rapid global spread in just a few months [2]. The WHO's Director-General declared COVID-19 a Public Health Emergency of International Concern on January 30, 2020, and later as a pandemic on March 11, 2020, urging all countries to take urgent and aggressive actions for detecting, tracing, isolating, and treating active cases, and for preventing transmission to reduce COVID-19-related morbidities and mortalities [3]. As of May 19, 2020, there have been around 4.7 million laboratory confirmed cases of COVID-19 reported across the world [4]. This novel coronavirus first arrived on the African continent in February, with the first few cases detected in Egypt and Algeria [5]. As of May 19, 2020, all WHO African Region member states are affected with 47,953 confirmed cases and 1488 reported deaths with a case-fatality ratio of 3.1% [6].

During any disease outbreak or health emergency, timely access to validated data and its translation into evidence to support swift public health actions and decision making is one of the biggest challenges faced by many public health experts, especially in resource-poor settings. This is especially true for settings where routine public health surveillance systems are underperforming or nonexistent, or may be disrupted during the COVID-19 crisis. Such delays in outbreak control during an emergency response results in delayed case detection and public health actions to mitigate onward transmission. Consequently, higher mortalities with higher rates of disease transmission in communities are inevitable. To address such delays, the WHO recommends implementation of a disease early warning system, known as the Early Warning, Alert and Response System (EWARS), within 3-10 days of the onset of an emergency's acute phase as one of the priority interventions to mitigate the negative health consequences resulting from the acute emergency or humanitarian event [7].

The EWARS system supports any existing health system and facilitates collection of essential, minimal data on prioritized epidemic-prone or selected diseases with significant public health consequences to enable rapid analysis of trends for outbreak or emergency responses in humanitarian settings. Enhancing the EWARS system using robust electronic data systems could be harnessed as a powerful tool by outbreak response teams for collecting vital epidemiological data to support appropriate and timely action during emergencies. The WHO has developed various electronic tools and platforms such as the electronic Disease Early Warning System (eDEWS) and EWARS-in-a-Box to support EWARS surveillance data collection, management, and analysis to inform timely public health actions and evidence-based decision making in humanitarian settings. Furthermore, these electronic systems have been adapted to support the surveillance component of the electronic Integrated Disease Surveillance and Response (eIDSR) and to facilitate early detection of prioritized epidemic-prone diseases [8-10].

COVID-19 is a current focus of surveillance, contact tracing, and outbreak response strategies worldwide. These strategies seek to ensure early and timely identification of cases, their effective isolation, and rapid contact tracing to break the chain of transmission [11]. For this purpose, the WHO African Regional Office has prioritized use of Go.Data among existing WHO electronic data collection platforms in the COVID-19 outbreak context. This tool has been recently developed by the WHO in collaboration with partners in the Global Outbreak Alert and Response Network [12].

Go.Data is an outbreak investigation tool designed for flexibility in field data collection during public health emergencies. This tool provides functionality for case investigation, contact tracing, and visualization of transmission chains. It facilitates data collection about an outbreak of an infectious disease, including cases associated with that outbreak, events at which transmission of the disease may have occurred, contacts that have been at risk of infection through exposure to a case or event, and contact tracing to monitor their health following an exposure [12,13].

This electronic platform assists responders to choose the right interventions to stop the disease from spreading and to work smarter [14]. The key difference between Go.Data and other existing WHO electronic systems in the WHO African Region is that the Go.Data tool has been designed primarily to improve contact tracing activities to break disease transmission. It also has a functionality for visualization of transmission hierarchies. This is in contrast to other existing WHO electronic surveillance systems that have the primary focus to support EWARS functions as part of routine Integrated Disease Surveillance and Response (IDSR) activities [8,9,15].

The complete rollout of an electronic field data collection platform ranges from a couple of weeks to a month for planning, deployment, training, and support including regular technical advice in the WHO African Region. Potentially, this may leave a critical gap between the declaration of the onset of a COVID-19 outbreak and the start of data collection that is in line with operationalization delays reported with existing electronic platforms for EWARS [8,16-18]. Few earlier studies have highlighted a need to use an interim and rapidly deployable solution that could bridge the gap between outbreak onset and full implementation of electronic data systems. Studies also suggest considering poor technical capacity and issues with access and resources when implementing such interventions in resource-poor settings [8,17].

This paper discusses the process our team undertook to research and develop a tool that would bridge the data collection gap between the onset of an outbreak and the start of data collection using a prioritized electronic data collection platform (PEDCP). We developed the COVID-19 Data Summarization and Visualization (DSV) tool for this purpose. Currently, this DSV tool is used in the 18 countries of the WHO African Region to support the current COVID-19 outbreak response. Additionally, we highlight preliminary findings and lessons learned from the DSV tool deployment in the 18 countries in the WHO African Region.

Methods

Review

To inform prioritized development of the COVID-19 DSV tool and better understand functions of existing tools against targeted needs, we reviewed the use of existing WHO electronic platforms and software for EWARS, case-based surveillance, contact tracing, and other eIDSR-related surveillance activities during various outbreaks and health emergencies in the WHO African Region. These included EWARS-in-a-Box, eDEWS, and Go.Data. The purpose of the review was also to identify any existing minimum data system standards aligned with COVID-19 regional and global surveillance guidelines and protocols; to prioritize information needs for effective COVID-19 outbreak response, planning, and decision making; and to inform the design of the interim DSV solution to facilitate smooth transitioning to implementation and full deployment of a PEDCP [19,20].

The review was conducted through an online literature search for technical guidance documents and published data in PubMed/MEDLINE (Medical Literature Analysis and Retrieval System Online), and Google Scholar databases including the WHO library database; directly approaching WHO teams, by phone call, by emails, or in person, involved in designing and implementing these platforms in the WHO African Region; and informal focus group discussions with WHO operational staff, including members of field teams, managers, and leaders involved in field data collection and contact tracing during health emergencies such as Ebola virus disease in the

Democratic Republic of the Congo and West Africa, and other outbreaks in the WHO African Region.

DSV Tool Design

As a result of our review, we identified the following seven key considerations essential in the development of the tool.

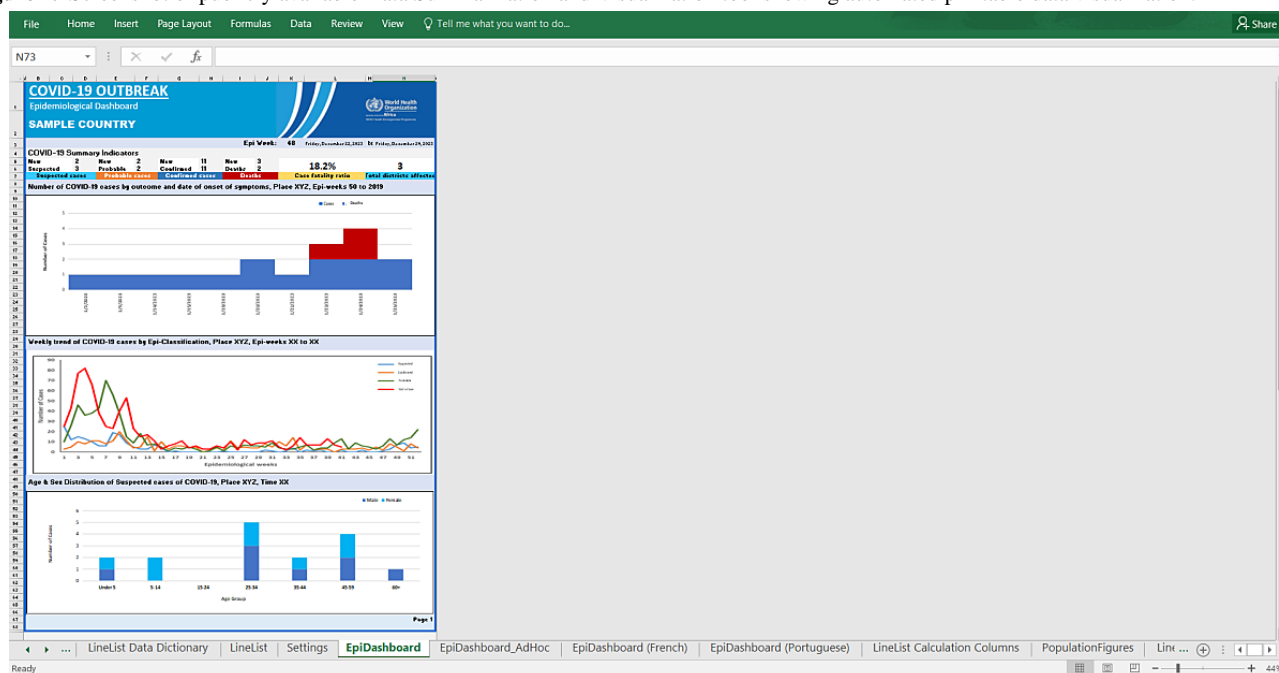
1. Inclusion of WHO standard data needs and priorities for the COVID-19 response in the African Region
2. Challenges around field data collection, management, analysis, and visualization during the COVID-19 outbreak in member states
3. Reporting requirements under the WHO International Health Regulations (2005), namely data flow from the field to country to regional office
4. Facilitate smooth deployment of robust data collection and contact tracing solution for case-based reporting
5. Challenges around frequent staff turnover and training needs
6. Lack of basic infrastructure with key technical, political, and financial considerations
7. Ease of use, sustainability, and local ownership

We also concluded that the tool must be specifically designed for interim use, rapidly deployable, cost effective, and time efficient.

The DSV tool was developed as part of the WHO Regional Office for Africa (AFRO) initiative "Outbreak Toolkits," available publicly at the WHO outbreak toolkit web portal [21], that was adapted later at the WHO Global level for replication in the global perspective in other WHO regions across the world [22,23] (Figures 1 and 2).

Figure 1. Screenshot of publicly available web portal of the World Health Organization Regional Office for Africa Toolkit Project.



Figure 2. Screenshot of publicly available Data Summarization and Visualization tool showing automated printable data visualization.

Results

Development

We concluded based on our review that the DSV tool must be specifically designed for interim use, rapidly deployable, cost effective, and time efficient. The DSV tool was developed in line with the WHO Global COVID-19 Surveillance Guidelines and Protocols and adapted to the WHO African Region requirements. It assists member states in the collection, reporting, analysis, and interpretation of data *immediately* upon onset of any COVID-19 outbreak. The tool is simple, customizable, adaptable, and easy to implement for interim use.

We developed the DSV tool using Excel (Microsoft Corporation). This tool uses preformatted pivot tables with automation that is simple to use, requiring basic Excel skills at the end-user level. In phase two of the DSV tool deployment, we built automation processes to support export and integration of multiple COVID-19 data files for sharing by member states and to be merged into one central COVID-19 database for use at the WHO regional level. This DSV tool is located on a publicly available web portal for the COVID-19 WHO AFRO Outbreak Toolkit [13].

Description of DSV Tool Modules

The DSV tool consists of modules for data collection, automated data management and analytics, and visualization. A brief description of each module follows.

Data Collection Module

We created the data collection tool using an Excel spreadsheet in the line listing format. We also created optional XLSForms for use in KoBoCollect, ODK, or other similar platforms for settings with prior XLSForm user experience and existing resources to use such platforms immediately. This allows flexibility for users either to enter data directly into formatted Excel worksheets with validation checks and conditional rules

or to use XLSForms with recommended ODK or KoBoCollect platforms for data entry using electronic devices as an option.

Automated Data Management and Analytics Module

We created preformatted pivot tables with functionality to automatically extract the significance from a large, detailed data set; summarize it into tables; and then use canned pivot analysis for rapid multidimensional and meaningful high-level analysis of data. We kept flexibility to allow an ad hoc type of data handling and analysis as needed.

One-Click Spreadsheet Visualization: COVID-19 Dashboard

To help with data analysis and interpretation, we created preformatted single-click visualizations and locked layouts of the COVID-19 dashboard to facilitate printing of the dashboard in PDF format and quickly share initial and high-level summary with health emergency managers, leadership, and other stakeholders in the WHO African Region.

Multilingual Support

This includes templates in three languages English, French, and Portuguese to address the priority languages used in the WHO African Region.

Using the DSV Tool as an Immediate Response for COVID-19 Outbreaks

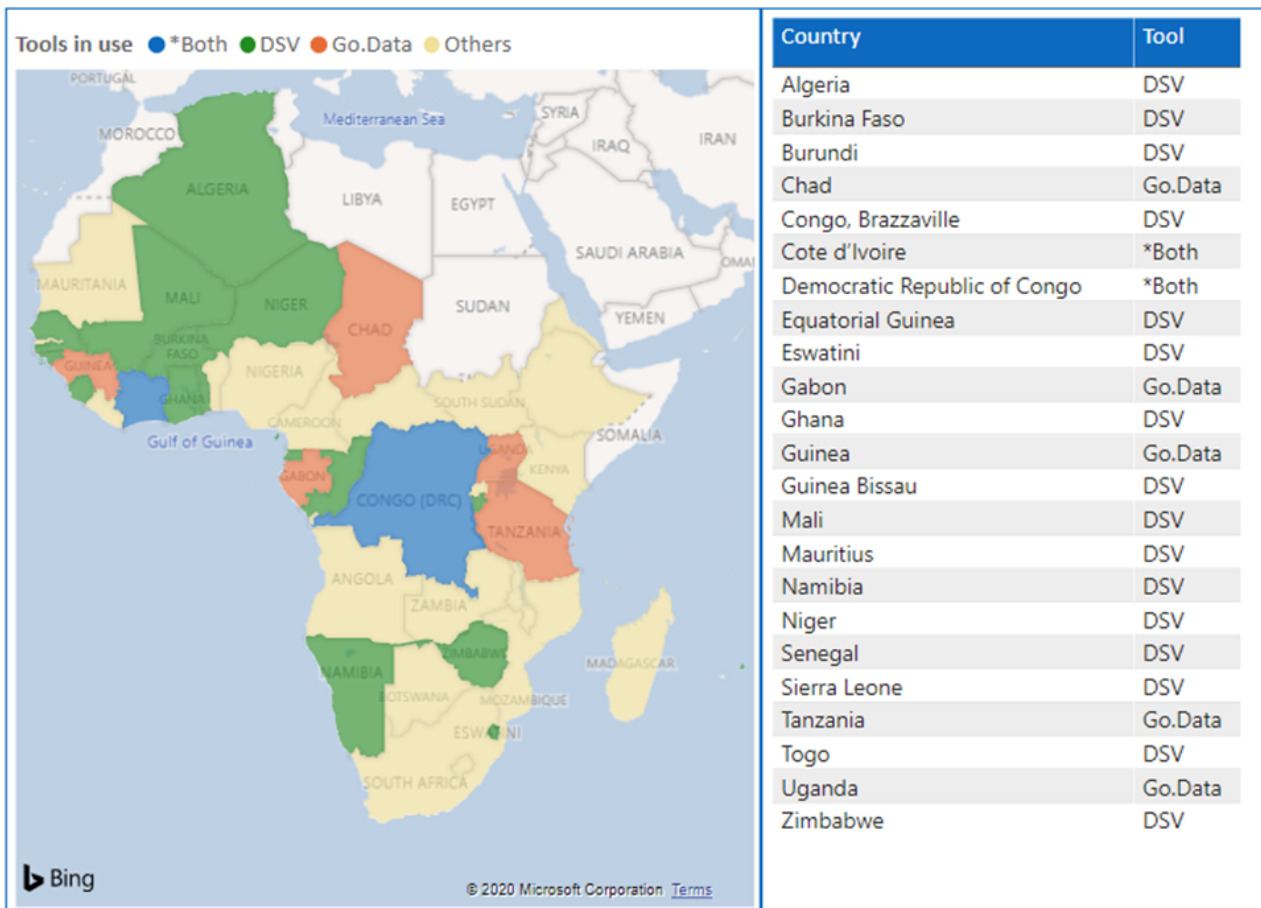
It is specifically recommended that the DSV tool is immediately deployed upon confirmation of the first COVID-19 case within the African Region. Rapid deployment will support the rollout of a prioritized electronic tool, which is currently facing delays due to country-applied public health and social measures including movement restrictions and geographical area quarantine in settings lacking basic infrastructure and necessary resources. To facilitate immediate reporting with the DSV tool, we have also developed preconfigured XLSForms in multiple languages to be used with KoBoCollect, ODK, or any other

platform that supports XLSForm configurations to facilitate real-time collection of data from the field using electronic devices and kept as an optional feature for use.

The main objective of developing the DSV tool was to provide an interim solution for immediate deployment during the COVID-19 outbreak response for field data collection, contact tracing follow-up, and generating epidemiological information for decision makers in a timely manner. As shown in Figure 3,

as of May 10, 2020, the DSV tool has been deployed in 18 member states in the WHO African Region and has been shared with other member states as part of a readiness and preparedness package. The interim use of the DSV tool is recommended to avoid delays in settings where technical infrastructure and constraints on resources remain major barriers to launching any electronic data collection platform for COVID-19 case-based surveillance.

Figure 3. Map showing the status of COVID-19 data collection tools deployed by the World Health Organization African Regional Office in the member states, as of April 2020. DSV: Data Summarization and Visualization.

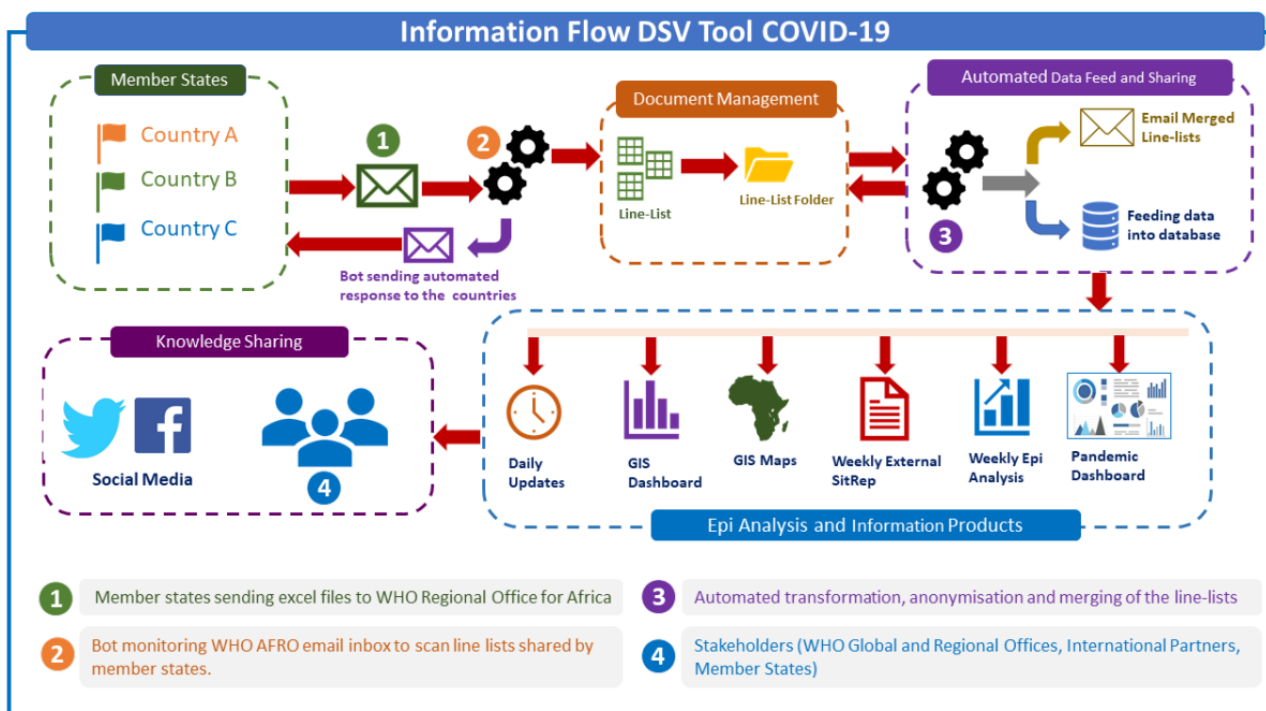


Automation for COVID-19 Data Management for Decision Making

Figure 4 shows how data extracted using the DSV tool flows from member states to the WHO AFRO office. At the WHO AFRO office, all COVID-19 data in Excel files are received via email after the data validation process at the WHO country offices are completed and stored using an automated document management platform. At the WHO AFRO office, the COVID-19 data files are merged, compiled, and shared with the data analytics teams. The data are then translated into

information using R analysis for evaluation, synthesized into evidence, and stored in an online-integrated data warehouse with a front-end web portal and COVID-19 dashboard. At this stage, synthesized information on the COVID-19 outbreak is translated into knowledge and shared with stakeholders (WHO global and regional offices, international partners, and member states) using authoritative products such as AFRO COVID-19 daily updates, weekly situation reports, weekly epidemiological updates, geographic information system maps, and COVID-19 pandemic dashboards.

Figure 4. Automation workflow showing management of COVID-19 data in the WHO African Region. AFRO: Regional Office of Africa; DSV: Data Summarization and Visualization; GIS: geographic information system; WHO: World Health Organization.

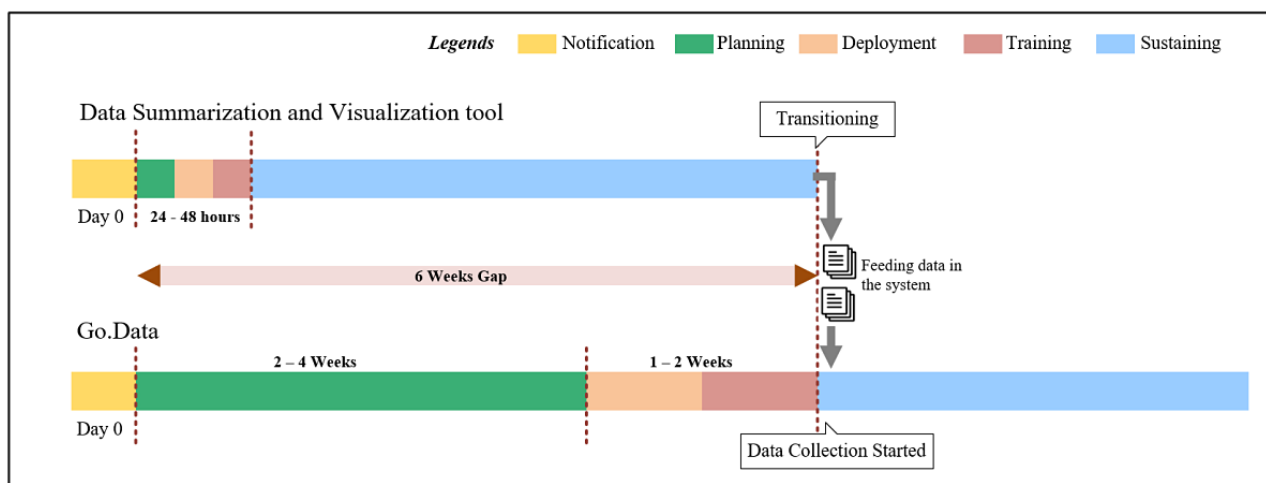


Transitioning Timeline

For a PEDCP, the planning, procurement, deployment, training, and support activities required resulted in a delayed rollout during the recent deployments in the WHO African Region. The planning phase usually includes predeployment reviews, requirement analysis, procurements, testing, and software configurations. This phase is followed by a software deployment, which includes infrastructure provisioning, software installation support, training of trainers, and customization and adaptation of data collection forms, after which the system goes live. The last phase is end-user training and maintenance with sustained software support to start data collection and maintain the system.

For the DSV tool, the simple preformatted Excel tool was shared with all member states in the WHO African Region as part of a readiness and preparedness package for the COVID-19 pandemic. The DSV tool comes with a quick user guide and takes 24-48 hours to customize for any additional requirements, with or without technical support from the WHO AFRO, and it is available for immediate data entry and visualization. The preformatted built-in automated analytics and visualization modules generate tables and charts in a PDF printable format. The deployment timeline comparison shows that the major benefit of the DSV tool is that it shortens tool deployment time and can be used to bridge the gap between data collection and contact tracing between the time of outbreak onset and the complete rollout of a robust electronic data collection software (Figure 5).

Figure 5. Timeline showing transitioning of Data Summarization and Visualization tool to Go.Data prioritized by the World Health Organization (WHO) Regional Office of Africa for COVID-19 field data collection in the WHO African Region.



Discussion

Principal Findings

The DSV tool is not a replacement for a robust electronic data collection platform. However, this tool provides outbreak investigation and response teams with a means to start collection of COVID-19 case, laboratory, hospitalization, and contacts data immediately upon confirmation of a COVID-19 outbreak. In addition, it generates analytical data and visualizations in a timely manner using an automated process that shows the COVID-19 outbreak situation for emergency health managers and decision makers. As an Excel-based tool, it is specifically recommended as an interim solution for short-term outbreak needs and not for use in protracted outbreaks or emergencies. The Go.Data tool has been deployed in some member states of the WHO African Region, where it took several weeks for implementation and complete rollout since technical support was not possible on the ground due to country-applied public health and social measures including movement restrictions and geographical area quarantine. The WHO AFRO is working closely with partners on a range of similar activities and finding ways to work around limitations imposed by travel restrictions and site presence.

The deployment of a PEDCP needs time for preparations, planning (requirement analysis, budget, and action plan), procurements, customizations, configurations, training, and support. This increases the inevitable time delay between onset of COVID-19 outbreak and complete rollout, especially in unprepared settings where electronic tool deployment has not been considered as part of a WHO AFRO country readiness and preparedness plan for a COVID-19 outbreak. This paper presents preliminary findings of this work, and an evaluation is planned, under the framework for the health emergency information management in the WHO African Region, to assess how well this intervention achieved its goals (simplicity, cost effectiveness, time efficiency, etc), what worked well, what did not work well, and how to improve the effectiveness of operations.

As part of preparedness and response, the WHO AFRO Health Information Management and Risk Assessment Program developed the DSV tool as an interim solution to support the immediate collection of case and contact data during the initial phase of a COVID-19 outbreak response. The main purpose of this tool was to bridge the critical time delay between a COVID-19 outbreak onset and PEDCP deployment for field data collection and contact tracing. To date, the DSV tool has been successfully implemented in 18 member states as an interim approach in parallel to planning for the Go.Data rollout as a prioritized electronic platform.

There are three main official languages (English, French, and Portuguese) spoken in the WHO African Region where the DSV tool was deployed. We developed built-in multilingual support in the DSV tool by including templates in these three official languages as a standard approach for the region. We have kept flexibility in the tool to add more language templates so other spoken local languages can be easily configured in the tool and facilitate immediate availability of translated text in the tool.

This functionality has been reported to be useful in overcoming the language barrier with implementation in the WHO African Region.

A workflow has been developed using automated tools at the WHO regional office to support merging of multiple COVID-19 data files coming from the member states into one master data set. Information management teams then use this master data set to perform analysis on the COVID-19 outbreak situation in the WHO African Region and produce authoritative information products. Additionally, this data is further integrated with other relevant information coming from other health pillars and evaluated in terms of broader stakeholders' needs and issues confronting the health emergency.

In the past few years, the WHO has developed and deployed multiple electronic data systems to support EWARS functions and routine disease surveillance, and these tools have been found to be effective and efficient informatics solutions in those settings. However, limitations have been reported in addressing some specific case-based surveillance and contact tracing needs [8,16]. We learned during the literature review and informed discussions that the EWARS-in-a-Box and eDEWS platforms were developed by the WHO with the objective of early detection and response to disease outbreaks during health emergencies. These platforms produced encouraging results with scaling up to other countries for EWARS and IDSR programs. However, both systems were not designed to support collection and management of complex contact tracing data to break the community disease transmission [8,9,15,18]. On the contrary, Go.Data has been designed to address this critical gap along with a focus on collecting and managing complex contact tracing data efficiently with visualization tools to support response efforts more effectively during outbreaks and emergencies [12].

Finally, the DSV tool provides an innovative and low cost simple analytical and visualization interim solution for data collection and management. The cost was low because this project was developed and implemented without dedicated funds and only used existing infrastructure and resources at the WHO regional office, the WHO country offices, and health authorities in the member states. The DSV tool successfully bridges the critical gap between COVID-19 outbreak onset and PEDCP operationalization to avoid delays in getting critical COVID-19 data in a timely manner during this period, facilitate timely access to validated COVID-19 data, and enable translation of data into actionable information to support swift public health response and decision making both at the country level and at the WHO African regional office. The DSV tool is easily and immediately deployable in practice using existing infrastructure and resources, and has been developed using a time efficient Excel pivot table technique that requires basic Excel skills at the end-user level, and tool standardization using the WHO regional and global guidelines and protocols makes it usable across all member states in the WHO African Region. We avoided the use of Visual Basic for Applications (VBA) macros to address possible tool performance issues and made it compatible with multiple versions ranging from Excel 2013 to Excel for Office 365, including compatibility with multiple operating systems. The built-in visualization module generates

automated epidemiological reports on a timely and ad hoc basis, an important public health informatics approach to perform well during the COVID-19 emergency. Building local capacity to use the DSV tool for complete data analysis, visualization, and reporting is easy using remote webinar sessions where basic Excel knowledge is considered essential for health staff participation. The DSV approach also improved timeliness of information sharing on epidemiological trends and feedback to field teams and key stakeholders involved in the outbreak response.

Lessons Learned

Drawing on the WHO AFRO team's experience in planning and conducting DSV tool deployment activities in 18 member states, we describe the following critical lessons learned and offer an opportunity to learn and apply these lessons to improve future similar public health informatics initiatives, including (but not limited to) COVID-19, at any outbreak or similar humanitarian setting.

The deployment of the DSV tool was smooth since most of the data managers in the WHO African Region are familiar with Excel-based tools and quickly adapted the DSV tool using technical guidance guidelines provided for the local COVID-19 outbreak context. The main concern shared by the data management team was that a reasonable number of variables be collected by the tool in considering the impact on staff workload and that the more than 50 variables proposed in the COVID-19 surveillance guidelines presented a challenge. Another challenge was to identify minimum standard variables in the WHO African regional context from the list of 87 variables recommended for COVID-19 surveillance in the WHO technical guidance document [24]. The tool was then designed to ease the workload for data entry, where we identified 22 minimum standard variables as required inputs and kept other variables as optional, based on feedback provided during the deployment in member states.

During the planning phase, our technical staff experienced in-field data collection in the WHO African Region suggested to limit end user exposure with VBA-enabled functions to avoid potential tool performance issues since, based on experience, it is not reliable. However, use of macro-enabled workbooks can give better results when adapted in small scale only. Another notable observation to highlight here is that, when considering bulk data entry, users expressed a preference for spreadsheet applications over form-based data entry applications. Spreadsheets are quick and flexible to establish and adapt, and they allow faster data entry through the use of copy and paste, and drag and drop functionalities to facilitate data entry and manipulation. Despite offering benefits such as more robust data validation, form-based data entry applications require more technical skills to establish and typically only allow working on a single observation at a time and thus take considerably longer when manipulating large volumes of data.

A common technical issue with the DSV tool was experienced by some member states. It was reported that there were problems handling date systems (1904 and 1900) compatibility between

operating systems Macintosh, iOS, and Windows. This compatibility issue did not affect data entry processes using the DSV tool but required careful processing when compiling workbooks generated from different operating systems. To resolve this issue permanently, we developed a VBA-based plug-in and installed it in the DSV tool as an update.

The adoption of the DSV tool was smoother in countries where the WHO country office data management teams had stronger relationships with their Ministry of Health counterparts. Building on existing working relationships enabled faster collaboration and decision making on the selection of data collection tools and establishment of data collection processes and reporting channels. Furthermore, member states that are stronger in surveillance have tended to require less support for establishing data collection platforms and are better able to leverage and integrate existing investments in IDSR toward outbreak response. Therefore, there is a need for strengthening data management capacity in member states with weak surveillance mechanisms. The team observed limitations within some countries for establishing data collection systems, defining and documenting data management processes, integrating data from multiple sources, and managing line lists. Some of these challenges manifested from limited expertise, lack of well-defined standard operating procedures for data management in the context of outbreaks, lack of clearly defined roles and responsibilities within and across teams, and slow activation and repurposing of existing staff onto the COVID-19 response.

Limitations

Two slightly different naming approaches have been used in the past for the same concept of the WHO's EWARS, a component of an integrated disease surveillance during various health emergencies across the world. These names are EWARS, Disease Early Warning System, and Early Warning, Alert and Response Network (EWARN). To keep consistency across the paper, we have used the term "EWARS" from the most recent naming convention in the WHO's Emergency Reforms Framework, but the concept of EWARN is the same as EWARS and should not be confused when referring to other earlier papers.

Conclusion

In conclusion, we developed an innovative tool for time efficient COVID-19 data collection, management, summarization, and visualization for immediate deployment in COVID-19 outbreak settings of member states in the WHO African Region. The automation process was introduced to facilitate timely knowledge sharing with response teams and decision makers, who rely on timely and accurate information for evidence-based decision making. The approach and processes used in, and the lessons learned from, this paper are generalizable to other health emergencies and need to be considered as an interim solution for rapid deployment and immediate field data collection needs while deployment of an electronic platform or software like Go.Data, EWARS-in-a-Box, or eDEWS is planned for the next health emergency.

Conflicts of Interest

None declared.

References

1. Naming the coronavirus disease (COVID-19) and the virus that causes it. World Health Organization. 2020. URL: [https://www.who.int/emergencies/diseases/novel-coronavirus-2019/technical-guidance/naming-the-coronavirus-disease-\(covid-2019\)-and-the-virus-that-causes-it](https://www.who.int/emergencies/diseases/novel-coronavirus-2019/technical-guidance/naming-the-coronavirus-disease-(covid-2019)-and-the-virus-that-causes-it)
2. COVID-19 dashboard by the Center for Systems Science and Engineering (CSSE) at Johns Hopkins University (JHU). Johns Hopkins Coronavirus Resource Center. 2020. URL: <https://coronavirus.jhu.edu/map.html> [accessed 2020-05-19]
3. WHO Director-General's opening remarks at the media briefing on COVID-19 - 11 March 2020. World Health Organization. 2020 Mar 11. URL: <https://www.who.int/dg/speeches/detail/who-director-general-s-opening-remarks-at-the-media-briefing-on-covid-19---11-march-2020> [accessed 2020-05-19]
4. Coronavirus disease (COVID-19) situation report– 120. World Health Organization. 2020 May 19. URL: https://www.who.int/docs/default-source/coronaviruse/situation-reports/20200519-covid-19-sitrep-120.pdf?sfvrsn=515cabfb_2 [accessed 2020-05-19]
5. COVID-19 situation update for the WHO African Region: external situation report 1. World Health Organization. 2020 Mar 04. URL: https://apps.who.int/iris/bitstream/handle/10665/331330/SITREP_COVID-19_WHOAFRO_20200304-eng.pdf [accessed 2020-05-19]
6. COVID-19 situation update for the WHO African Region: external situation report 11. World Health Organization. 2020 May 12. URL: https://apps.who.int/iris/bitstream/handle/10665/332078/SITREP_COVID-19_WHOAFRO_20200513-eng.pdf [accessed 2020-05-19]
7. Emergency response framework. World Health Organization. 2017. URL: <https://apps.who.int/iris/bitstream/handle/10665/258604/9789241512299-eng.pdf?sequence=1> [accessed 2020-05-19]
8. Ahmed K, Bukhari MAS, Altaf MD, Lugala PC, Popal GR, Abouzeid A, et al. Development and implementation of electronic disease early warning systems for optimal disease surveillance and Response during humanitarian crisis and Ebola outbreak in Yemen, Somalia, Liberia and Pakistan. *Online J Public Health Inform* 2019 Sep 09;11(2):e11 [FREE Full text] [doi: [10.5210/ojphi.v11i2.10157](https://doi.org/10.5210/ojphi.v11i2.10157)] [Medline: [31632605](https://pubmed.ncbi.nlm.nih.gov/31632605/)]
9. Early Warning, Alert and Response System (EWARS). World Health Organization. 2020. URL: <https://www.who.int/emergencies/surveillance/early-warning-alert-and-response-system-ewars> [accessed 2020-05-19]
10. Technical guidelines for integrated disease surveillance and response - third edition. World Health Organization. 2019 Mar. URL: <https://apps.who.int/iris/bitstream/handle/10665/325015/WHO-AF-WHE-CPI-05.2019-eng.pdf> [accessed 2020-05-19]
11. 2019 novel coronavirus (2019-nCoV): strategic preparedness and response plan. World Health Organization. 2020 Feb 03. URL: <https://extranet.who.int/sph/2019-novel-coronavirus-2019%E2%80%91ncov-strategic-preparedness-and-response-plan>
12. Go.Data: managing complex data in outbreaks. World Health Organization. 2020. URL: <https://www.who.int/godata> [accessed 2020-05-19]
13. COVID-19 outbreak toolkit. World Health Organization. 2020. URL: <http://outbreaktoolkits.rsis.afro.who.int/covid-19/> [accessed 2020-05-19]
14. About Go.Data. World Health Organization. 2020. URL: <https://www.who.int/godata/about> [accessed 2020-05-19]
15. Ahmed K, Altaf MD, Dureab F. Electronic infectious disease surveillance system during humanitarian crises in Yemen. *Online J Public Health Inform* 2014;6(1):e134. [doi: [10.5210/ojphi.v6i1.5083](https://doi.org/10.5210/ojphi.v6i1.5083)]
16. Sheel M, Collins J, Kama M, Nand D, Faktaufon D, Samuela J, et al. Evaluation of the early warning, alert and response system after Cyclone Winston, Fiji, 2016. *Bull World Health Organ* 2019 Mar 01;97(3):178-189C [FREE Full text] [doi: [10.2471/BLT.18.211409](https://doi.org/10.2471/BLT.18.211409)] [Medline: [30992631](https://pubmed.ncbi.nlm.nih.gov/30992631/)]
17. Ahmed K, Ajanga A, Saleh OA, Altaf MD, Popal GR. Application of an innovative data analytical approach to assessing the disease situation during crises in Somalia, Yemen and Pakistan. *Online J Public Health Inform* 2015 Feb 26;7(1):e101. [doi: [10.5210/ojphi.v7i1.5767](https://doi.org/10.5210/ojphi.v7i1.5767)]
18. Karo B, Haskew C, Khan AS, Polonsky JA, Mazhar MKA, Buddha N. World Health Organization Early Warning, Alert and Response System in the Rohingya Crisis, Bangladesh, 2017-2018. *Emerg Infect Dis* 2018 Nov;24(11):2074-2076. [doi: [10.3201/eid2411.181237](https://doi.org/10.3201/eid2411.181237)] [Medline: [30234479](https://pubmed.ncbi.nlm.nih.gov/30234479/)]
19. Global surveillance for COVID-19 caused by human infection with COVID-19 virus: interim guidance. World Health Organization. 2020 Mar 20. URL: <https://apps.who.int/iris/rest/bitstreams/1272502/retrieve> [accessed 2020-05-19]
20. The first few X cases and contacts (FFX) investigation protocol for coronavirus disease 2019 (COVID-19). World Health Organization. 2020 Feb 10. URL: <https://apps.who.int/iris/rest/bitstreams/1270901/retrieve> [accessed 2020-05-19]
21. Outbreak toolkits. World Health Organization. 2019. URL: <http://outbreaktoolkits.rsis.afro.who.int/> [accessed 2020-05-19]
22. WHO outbreak toolkit. World Health Organization. 2020. URL: <https://www.who.int/emergencies/outbreak-toolkit> [accessed 2020-05-19]

23. Outbreak toolkit: consultation meeting in the WHO African Region. World Health Organization Regional Office for Africa. 2020. URL: <https://www.afro.who.int/publications/outbreak-toolkit-consultation-meeting-who-african-region> [accessed 2020-05-19]
24. Data dictionary for case-based reporting form. World Health Organization. 2020. URL: <https://www.who.int/publications/m/item/data-dictionary-for-case-based-reporting-form>

Abbreviations

AFRO: Regional Office for Africa

DSV: Data Summarization and Visualization

eDEWS: electronic Disease Early Warning System

eIDSR: electronic Integrated Disease Surveillance and Response

EWARN: Early Warning, Alert and Response Network

EWARS: Early Warning, Alert and Response System

IDSR: Integrated Disease Surveillance and Response

MEDLINE: Medical Literature Analysis and Retrieval System Online

PEDCP: prioritized electronic data collection platform

VBA: Visual Basic for Applications

WHO: World Health Organization

Edited by T Sanchez; submitted 22.05.20; peer-reviewed by S De Leo, H Kondylakis; comments to author 02.07.20; revised version received 23.07.20; accepted 28.07.20; published 14.10.20.

Please cite as:

Ahmed K, Bukhari MA, Mlanda T, Kimenyi JP, Wallace P, Okot Lukoya C, Hamblion EL, Impouma B

Novel Approach to Support Rapid Data Collection, Management, and Visualization During the COVID-19 Outbreak Response in the World Health Organization African Region: Development of a Data Summarization and Visualization Tool

JMIR Public Health Surveill 2020;6(4):e20355

URL: <http://publichealth.jmir.org/2020/4/e20355/>

doi: [10.2196/20355](https://doi.org/10.2196/20355)

PMID: [32997641](https://pubmed.ncbi.nlm.nih.gov/32997641/)

©Kamran Ahmed, Muhammad Arish Bukhari, Tamayi Mlanda, Jean Paul Kimenyi, Polly Wallace, Charles Okot Lukoya, Esther L Hamblion, Benido Impouma. Originally published in JMIR Public Health and Surveillance (<http://publichealth.jmir.org>), 14.10.2020. This is an open-access article distributed under the terms of the Creative Commons Attribution License (<https://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in JMIR Public Health and Surveillance, is properly cited. The complete bibliographic information, a link to the original publication on <http://publichealth.jmir.org>, as well as this copyright and license information must be included.

Original Paper

Transmission Dynamics of the COVID-19 Epidemic at the District Level in India: Prospective Observational Study

Suman Saurabh¹, MBBS, MD; Mahendra Kumar Verma¹, MBBS, MD; Vaishali Gautam¹, MBBS, MD; Nitesh Kumar¹, MBBS, MD; Akhil Dhanesh Goel¹, MBBS, MD; Manoj Kumar Gupta¹, MBBS, MD; Pankaj Bhardwaj¹, MBBS, MD; Sanjeev Misra², MBBS, MS, MCh

¹Department of Community Medicine and Family Medicine, All India Institute of Medical Sciences, Jodhpur, India

²All India Institute of Medical Sciences, Jodhpur, India

Corresponding Author:

Suman Saurabh, MBBS, MD

Department of Community Medicine and Family Medicine

All India Institute of Medical Sciences

2nd Floor, Academic Building

342005

Jodhpur

India

Phone: 91 7766906623

Email: drsumansaurabh@gmail.com

Abstract

Background: On March 9, 2020, the first COVID-19 case was reported in Jodhpur, Rajasthan, in the northwestern part of India. Understanding the epidemiology of COVID-19 at a local level is becoming increasingly important to guide measures to control the pandemic.

Objective: The aim of this study was to estimate the serial interval and basic reproduction number (R_0) to understand the transmission dynamics of the COVID-19 outbreak at a district level. We used standard mathematical modeling approaches to assess the utility of these factors in determining the effectiveness of COVID-19 responses and projecting the size of the epidemic.

Methods: Contact tracing of individuals infected with SARS-CoV-2 was performed to obtain the serial intervals. The median and 95th percentile values of the SARS-CoV-2 serial interval were obtained from the best fits with the weibull, log-normal, log-logistic, gamma, and generalized gamma distributions. Aggregate and instantaneous R_0 values were derived with different methods using the EarlyR and EpiEstim packages in R software.

Results: The median and 95th percentile values of the serial interval were 5.23 days (95% CI 4.72-5.79) and 13.20 days (95% CI 10.90-18.18), respectively. R_0 during the first 30 days of the outbreak was 1.62 (95% CI 1.07-2.17), which subsequently decreased to 1.15 (95% CI 1.09-1.21). The peak instantaneous R_0 values obtained using a Poisson process developed by Jombert et al were 6.53 (95% CI 2.12-13.38) and 3.43 (95% CI 1.71-5.74) for sliding time windows of 7 and 14 days, respectively. The peak R_0 values obtained using the method by Wallinga and Teunis were 2.96 (95% CI 2.52-3.36) and 2.92 (95% CI 2.65-3.22) for sliding time windows of 7 and 14 days, respectively. R_0 values of 1.21 (95% CI 1.09-1.34) and 1.12 (95% CI 1.03-1.21) for the 7- and 14-day sliding time windows, respectively, were obtained on July 6, 2020, using method by Jombert et al. Using the method by Wallinga and Teunis, values of 0.32 (95% CI 0.27-0.36) and 0.61 (95% CI 0.58-0.63) were obtained for the 7- and 14-day sliding time windows, respectively. The projection of cases over the next month was 2131 (95% CI 1799-2462). Reductions of transmission by 25% and 50% corresponding to reasonable and aggressive control measures could lead to 58.7% and 84.0% reductions in epidemic size, respectively.

Conclusions: The projected transmission reductions indicate that strengthening control measures could lead to proportionate reductions of the size of the COVID-19 epidemic. Time-dependent instantaneous R_0 estimation based on the process by Jombert et al was found to be better suited for guiding COVID-19 response at the district level than overall R_0 or instantaneous R_0 estimation by the Wallinga and Teunis method. A data-driven approach at the local level is proposed to be useful in guiding public health strategy and surge capacity planning.

KEYWORDS

Epidemiology; SARS-CoV-2; COVID-19; serial interval; basic reproduction number; projection; outbreak response; India; mathematical modeling; infectious disease

Introduction

COVID-19 has emerged as the largest pandemic of the 21st century, with 30.7 million confirmed cases and approximately 950,000 deaths worldwide as of September 2020 [1]. India has become the second most affected country worldwide after the United States, with approximately 5.4 million confirmed COVID-19 cases [1]. COVID-19 is an emerging infectious disease, the first case being reported from Wuhan, China, in early December 2019 [2]. Various epidemiological studies are being performed to understand the transmission dynamics of the disease. Consequently, estimation of parameters such as the serial interval and basic reproduction number (R_0) is being used to guide control strategies and enable disease forecasting [3-5].

In the early phase of the COVID-19 pandemic, India adopted a policy of universal health facility-based isolation of all individuals infected with SARS-CoV-2 irrespective of symptomatic status. However, in view of the increasing number of COVID-19 cases, home isolation of asymptomatic and mild cases was introduced on May 10, 2020 [6]. Due to the emerging nature of the outbreak and the evolving control measures, it is important to achieve a detailed epidemiological understanding of the COVID-19 situation at the district level to guide control measures and surge preparedness on a real-time basis.

Current mathematical modeling approaches for epidemiological understanding of COVID-19 in India are based on aggregate data reported at the national and state levels [7-13]. Very often, conclusions based on large-scale data are not appropriate for designing interventions at the local level. Therefore, we aimed to study the transmission of COVID-19 at the district level by estimating the serial interval and to determine the most suitable method for R_0 estimation to support decision-making at the district level. We also aimed to demonstrate the feasibility of epidemic projection to guide COVID-19 response.

We studied the COVID-19 outbreak in the Jodhpur District of the state of Rajasthan in India. This mid-sized cultural and tourism hub is known as the gateway to the Thar Desert area in the northwestern part of India. Based on projection of 2011 census data to 2020 while assuming constant annual exponential growth, Jodhpur District has a population of 4.6 million, with an urban population of 1.6 million [14]. The first COVID-19 case in this district was reported on March 9, 2020, and at least one case has been reported daily since March 30, 2020.

Methods

Overview

We conducted a prospective observational study of the COVID-19 outbreak in Jodhpur, India. We used two data sources for the study. Firstly, serial intervals were estimated based on contact history of laboratory confirmed SARS-CoV-2

infected individuals. Secondly, the publicly available daily case count data were used together with the serial intervals to estimate R_0 and project the size of the epidemic over the next 30 days. Individuals meeting the definition of a suspected case of COVID-19 were tested with the real time reverse transcriptase-polymerase chain reaction (rRT-PCR) at our institute in Jodhpur, India, as per national guidelines [15]. People who tested positive for SARS-CoV-2 were further assessed for their contact history with known COVID-19 cases in their household. The serial intervals were estimated based on the length of time between the onset of symptoms of the identified infectors and infectees. For asymptomatic individuals, the date of collection of the first positive sample was taken as a proxy of symptom onset.

The basic reproduction number (R_0) is defined as the average number of susceptible individuals infected by a single primary case [16]. For R_0 estimation, serial interval values along with daily case count data were taken from the official daily report released by the Jodhpur District administration. These data are also available on the internet [17].

Ethical Approval

Informed consent was obtained prior to eliciting contact history for serial interval estimation. The study was approved by the Institutional Ethics Committee (Ref: AIIMS/IEC/2020-21/3047).

Serial Interval Estimation

The mean (SD) of the serial intervals was calculated. Further, the serial interval data were fitted to weibull, log-normal, log-logistic, and generalized gamma distributions using the Flexsurv package in R software version 4.0.0 [18]. The estimates of the median serial interval were taken from the best-fitting model based on the minimum Akaike information criterion (AIC) value. The standard maximum likelihood approach was used to obtain the best model fit to the actual data.

Estimation of R_0

The daily COVID-19 case data in Jodhpur District were converted to incidence objects using the Incidence package in R software [19]. The EarlyR and EpiEstim packages in R were used to estimate the overall and instantaneous values of R_0 , respectively, using the parameter estimates of the serial interval [20,21]. We used two main standard methods of estimation of the instantaneous R_0 values to visualize their response to changes in case trends and to assess their utility for understanding real-time transmission dynamics at a local level. These methods use different mathematical modeling principles and assumptions.

Instantaneous R_0 values were first calculated using the method of estimating daily incidence based on a Poisson process determined by daily infectiousness, as proposed by Jombart et al [19] and Nouvellet et al [22]. Here, λ_t , the force of infection observed on day t , is expressed by the following equation:



where y_s is the incidence of cases on day s and R_s is the instantaneous reproduction number on day s . The value of ω_{t-s} is the probability mass distribution of the serial interval, which represents the infectiousness of incident cases on day s to result in secondary cases on day t . In the absence of an exhaustive symptomatic history of each reported case, we approximated the day the case was reported as the day of onset, a practical approach used in earlier studies [22].

Next, we used a method described by Wallinga and Teunis [23] to estimate the time-varying R_0 based on the probability of transmission between infector-infectee pairs. We adopted the parametric method of specifying the mean (SD) of the serial interval distribution for both methods. Time windows of 7 days and 14 days were used to calculate the instantaneous R_0 .

Forecasting of the Epidemic Size

The numbers of daily and cumulative COVID-19 cases for the next 30 days were forecasted based on the overall R_0 value and the R_0 value for the past 30 days as input parameters using the projections package in R [19]. The observed serial interval distribution was specified as the scale and shape parameters of the gamma distribution. Daily COVID-19 cases were predicted based on a Poisson process determined by daily infectiousness [22]. The specified serial interval distribution was taken as a prior while using the Bayesian methodology for Markov chain Monte Carlo sampling using the Metropolis algorithm. The 95%

CI of the projected daily and cumulative incidences were calculated using the bootstrap resampling method with 1000 samples.

Further, we considered two scenarios: one with a reasonable reduction of 25% SARS-CoV-2 transmission and one with an aggressive reduction of 50% transmission. A reasonable reduction would be related to compliance with strengthening of existing measures, such as contact tracing, testing, and prompt isolation of infected individuals along with physical distancing measures. Aggressive transmission reduction measures included universal mask-wearing and measures to reduce outdoor transmission through prevention of gatherings: closures of places of worship, marketplaces, restaurants, schools, and gymnasiums, along with introduction of nighttime curfews [24].

Results

Serial Interval

From the reporting of the first case of COVID-19 in Jodhpur District on March 9, 2020, to July 6, 2020, 3178 cases were reported in the district in a span of 120 days (see Figure 1). Serial interval data for 103 infector-infectee pairs were obtained through contact tracing of known infected cases (Multimedia Appendix 1).

The mean serial interval was 6.23 days (SD 3.49). The generalized gamma distribution was found to best fit the serial interval and showed the minimum AIC value (see Table 1).

Figure 1. Numbers of COVID-19 cases reported daily in Jodhpur, India, from March 9 to July 6, 2020.

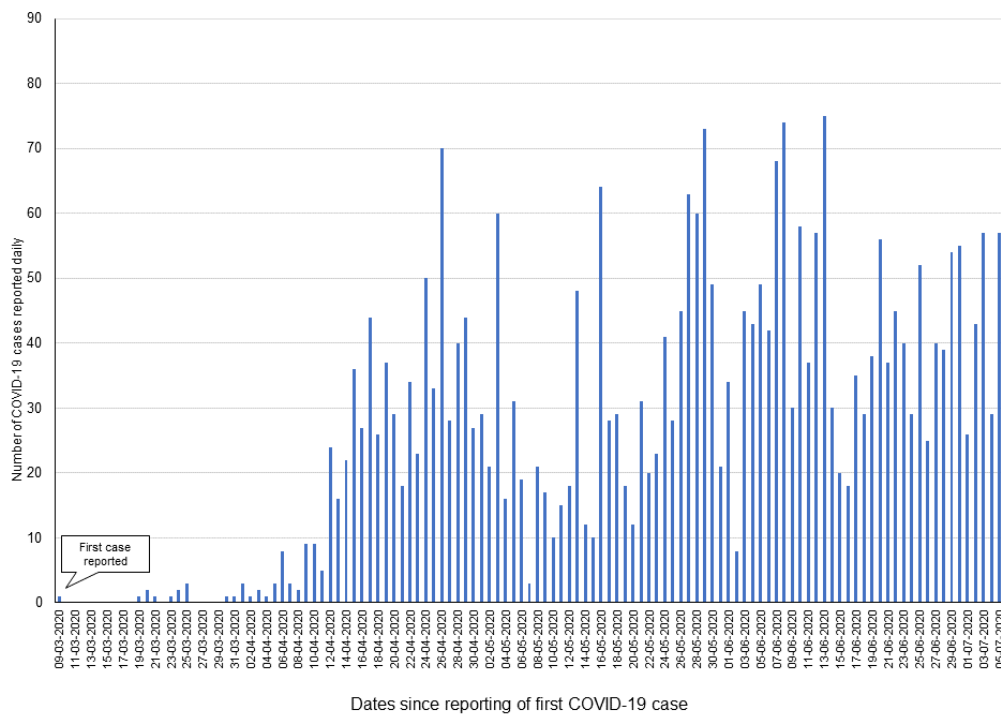
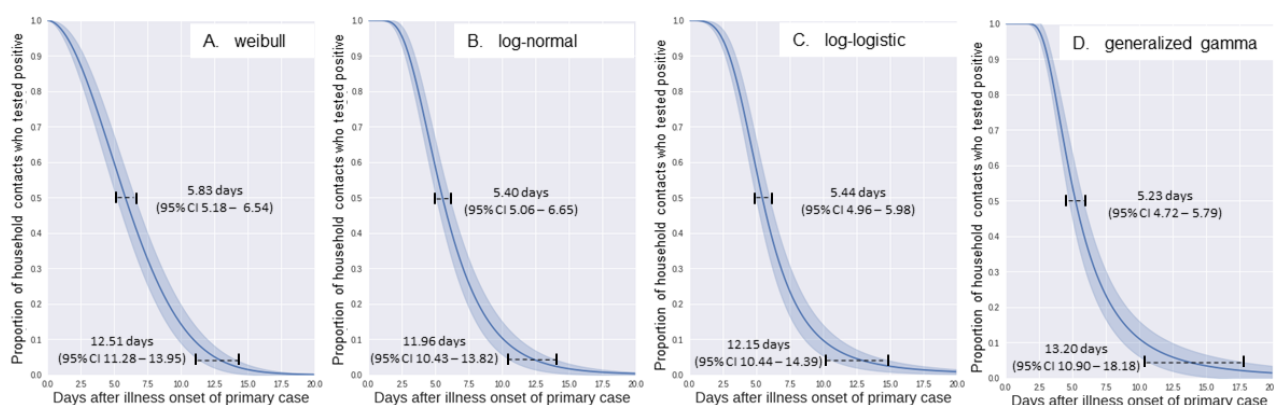


Table 1. Fits of weibull, log-normal, log-logistic, and generalized gamma distributions with the serial interval data for SARS-CoV-2 infection in Jodhpur District, India, and the estimated median and 95 percentile values (N=103 pairs).

Type of distribution used in the model	-2 log-likelihood	Number of model parameters (k)	AIC ^a (-2 log-likelihood + 2k)	Serial interval (days)	
				Median (95% CI)	95th percentile (95% CI)
Weibull	520.30	2	524.30	5.83 (5.18-6.54)	12.51 (11.28-13.95)
Log-normal	488.55	2	492.55	5.40 (5.06-6.07)	11.96 (10.43-13.82)
Log-logistic	492.46	2	496.46	5.44 (4.96-5.98)	12.15 (10.44-14.39)
Gamma	500.15	2	504.15	5.77 (5.23-6.33)	11.79 (10.52 -13.22)
Generalized gamma	482.97	3	488.97	5.23 (4.72-5.79)	13.20 (10.90-18.18)

^aAIC: Akaike information criterion.

The median and 95th percentile values of the serial interval were 5.23 days (95% CI 4.72-5.79) and 13.20 days (95% CI 10.90-18.18), respectively, estimated from the fitted generalized gamma distribution (see [Figure 2](#)).

Figure 2. Estimates of the median and 95th percentile of the serial interval data fitted to (A) weibull, (B) log-normal, (C) log-logistic, and (D) generalized gamma distributions (N=103 pairs).

Estimation of R_0

The overall R_0 value in the 30 days after the first case was reported was 1.62 (95% CI 1.07-2.17), which subsequently decreased to 1.15 (95% CI 1.09-1.21). The overall R_0 value for the entire outbreak duration was 1.07 (95% CI 1.04-1.11), whereas it was 1.20 (95% CI 1.14-1.27) in the last 30 days.

The time-dependent instantaneous R_0 values calculated using the method by Jombart et al [19] and Nouvellet et al [22] yielded maximum values of 6.53 (95% CI 2.12-13.38) and 3.43 (95% CI 1.71-5.74) using sliding time windows of 7 days and 14 days, respectively (see [Table 2](#) and [Figure 3](#)). Similarly, using the method described by Wallinga and Teunis [23], the maximum values of the instantaneous R_0 were 2.96 (95% CI 2.52-3.36)

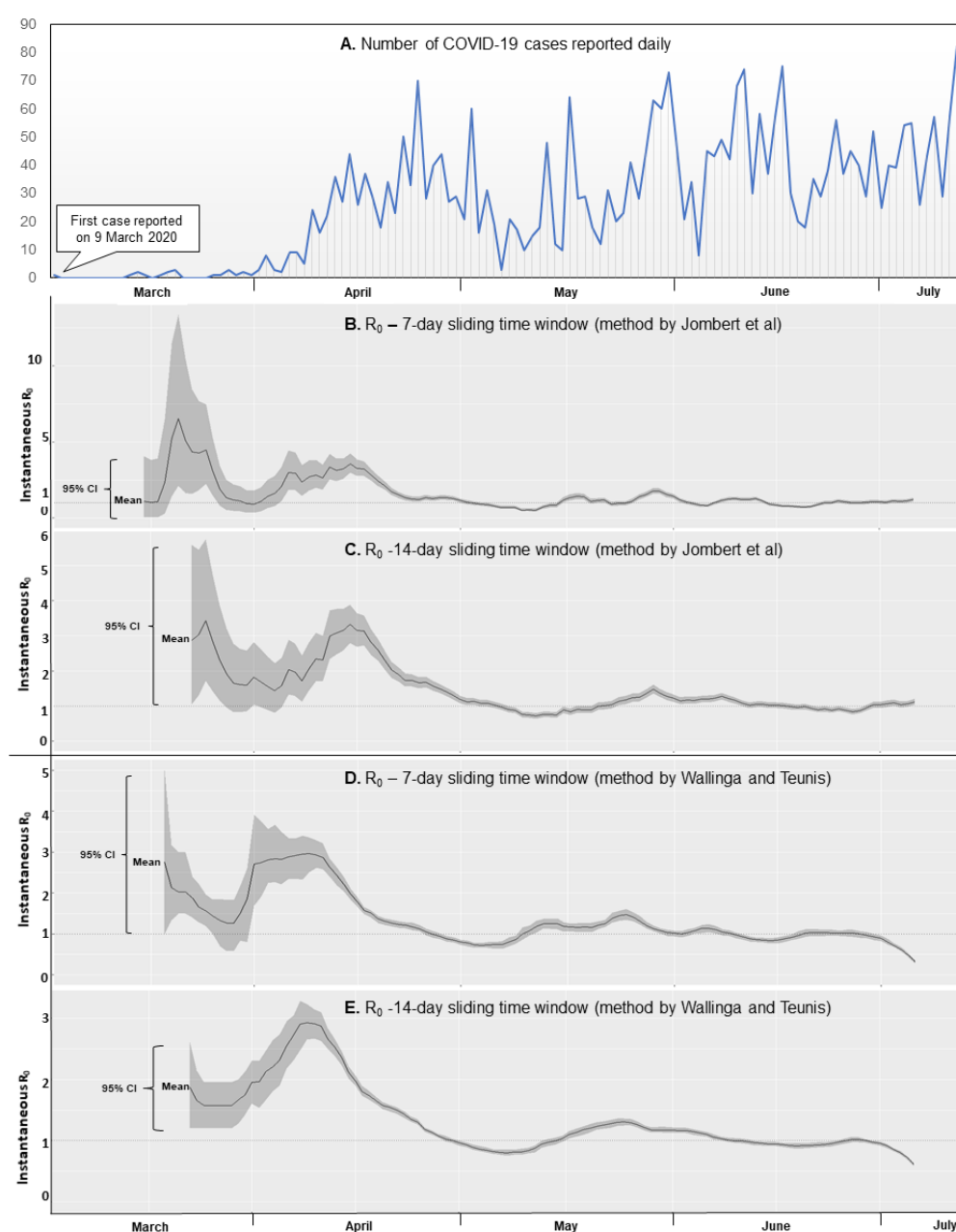
and 2.92 (95% CI 2.65-3.22) for the 7- and 14-day time windows, respectively (see [Table 2](#) and [Figure 3](#)). The peak R_0 values corresponded with the daily rising trend in COVID-19 cases that was reported (see [Figure 3](#)).

The latest instantaneous R_0 values estimated on July 6, 2020, using the method by Jombart et al [19] and Nouvellet et al [22], were 1.21 (95% CI 1.09-1.34) and 1.12 (95% CI 1.03-1.21) for 7- and 14-day sliding time windows, respectively (see [Table 2](#) and [Figure 3](#)). Similarly, the latest instantaneous R_0 values estimated on July 6, 2020, using the method by Wallinga and Teunis [23] were 0.32 (95% CI 0.27-0.36) and 0.61 (95% CI 0.58-0.63), for the 7- and 14-day sliding time windows, respectively (see [Table 2](#) and [Figure 3](#)).

Table 2. Summary of the time-dependent R_0 values estimated by the different methods.

Method used and sliding time windows	Minimum value (95% CI)	Maximum value (95% CI)	Latest value as of July 6, 2020 (95% CI)
Jombart et al and Nouvellet et al			
7-day	0.52 (0.42-0.62)	6.53 (2.12-13.38)	1.21 (1.09-1.34)
14 day	0.72 (0.64-0.80)	3.43 (1.71-5.74)	1.12 (1.03-1.21)
Wallinga and Teunis			
7-day	0.32 (0.27-0.36)	2.96 (2.52-3.36)	0.32 (0.27-0.36)
14-day	0.61 (0.58-0.63)	2.92 (2.65-3.22)	0.61 (0.58-0.63)

Figure 3. Daily COVID-19 cases in Jodhpur District, India, from March 9 to July 6, 2020 (A), instantaneous R_0 values estimated using the method by Jombart et al (B-C), and instantaneous R_0 values estimated using the method by Wallinga and Teunis using time windows of 7 and 14 days, respectively (D-E).



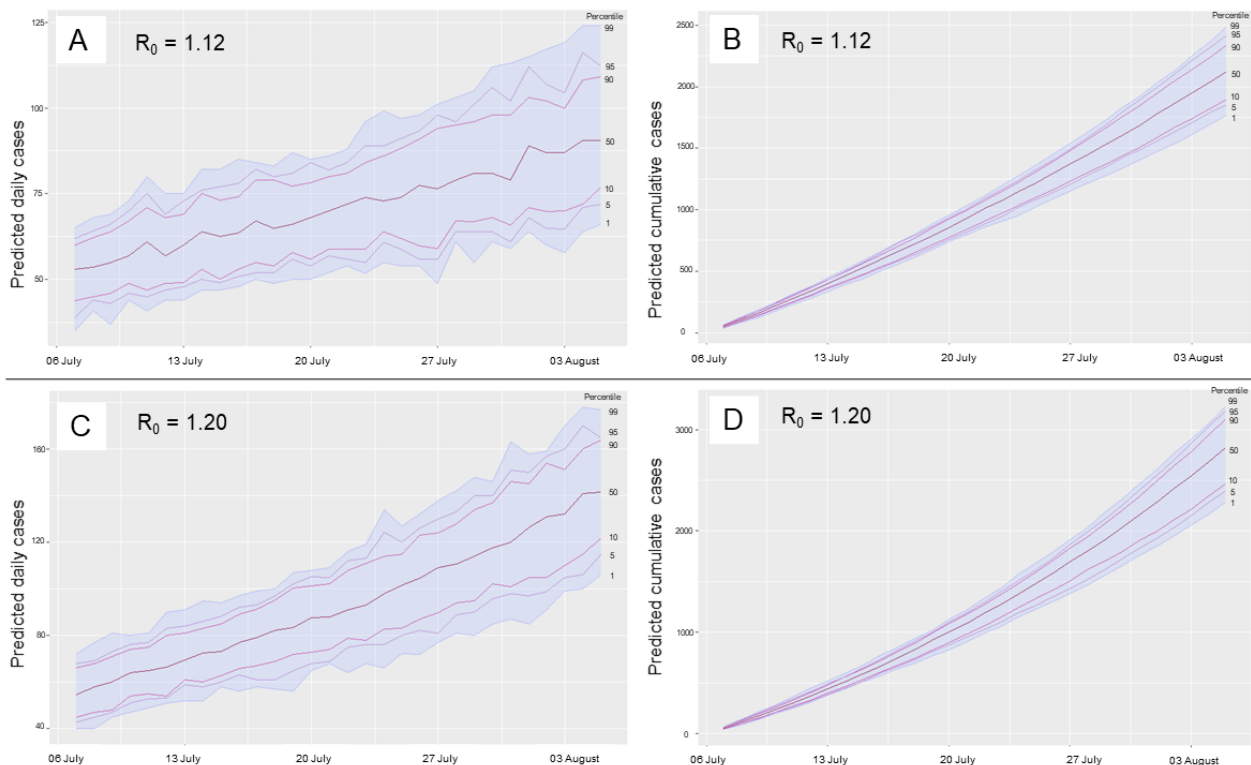
Projection of Epidemic Size

The number of daily cases projected for the next month based on an overall R_0 value of 1.20 (corresponding to the most recent 30 days of transmission) ranged from 55 (95% CI 38-71) on July 7, 2020 (day 1), to 143 (95% CI 110-175) on August 5, 2020, (ie, on day 30; see Figure 4). Similarly, the number of daily cases projected for the next month while taking the most recent 14-day rolling instantaneous R_0 value of 1.12 ranged from 52 (95% CI 38-66) on day 1 to 91 (95% CI 66-116) on day 30 (see Figure 4). The cumulative projections of the number

of COVID-19 cases over the next 30 days using the R_0 values of 1.20 and 1.12 were 2817 (95% CI 2374-3259) and 2131 (95% CI 1799-1462), respectively.

The scenarios of 25% and 50% transmission reduction of the most recent time-dependent R_0 estimate (ie, reduction of R_0 from 1.12 to 0.84 and 0.56, respectively) resulted in monthly projections of 880 cases (95% CI 699-1061) and 341 cases (95% CI 265-418); these projections correspond to 58.7% and 84.0% reductions in the epidemic size in Jodhpur, respectively.

Figure 4. Projections of daily and cumulative COVID-19 caseloads over the next 30 days using the instantaneous R_0 value of 1.12 on July 6, 2020 (A-B) and the overall R_0 value of 1.20 for the most recent 30 days (C-D).



Discussion

Implications of the Serial Interval and Estimated R_0 Values

Our observation of the mean serial interval fell within a range of 4 to 8 days, as estimated by a meta-analysis of 7 studies conducted during the early phase of the COVID-19 pandemic [25]. Another meta-analysis including studies only from China estimated a range of serial intervals from 4.10 to 7.5 days [26]. Our experience suggests that the median and 95% CI estimates of the serial interval should be reported alongside the mean and SD, as the latter approach is more susceptible to influence by extreme values. It has also been suggested that longer serial interval intervals may be due to preventive interventions introduced during the course of the epidemic, which tend to reduce transmission [27,28]. Therefore, it is preferable to estimate the recent serial interval at a local level to better understand the transmission of SARS-CoV-2.

The distribution of R_0 values was consistent with observations from other countries, indicating a similar transmission pattern [4,28]. The peak of the R_0 value was reached in the first week of April 2020. The subsequent reduction toward the end of April can be attributed to aggressive testing, contact tracing, and isolation measures implemented in the urban area of Jodhpur during that month. Our R_0 estimate for the first month (1.61) was slightly higher than the national estimate of 1.47 and lower than the estimate from the state of Tamil Nadu (1.88) in India during the same period of March to April 2020 [9,13]. District level R_0 estimates are more likely to show pronounced fluctuations than state or national estimates, as the latter are aggregated across a wide range of epidemiological settings. Because district-level R_0 estimates were not available from India, we compared our findings with those from the cities of Qom and Shahrud in Iran [29,30]. Similar to these cities, Jodhpur showed a trend of high values of R_0 in the first 14-30 days, with a subsequent decrease toward 1 [29,30]. The initially high R_0 values can be attributed to the suddenness of the outbreak if the surveillance system is robust. The high values

may also be due to a sudden start of case reporting following an initial period of underreporting, leading to an artefactual peak in R_0 [30].

Earlier detection of infection followed by isolation is known to reduce the R_0 value by limiting both the duration of effective contact and the number of susceptible people an infected individual can come in contact with [16]. Our findings further support that parameters such as the serial interval, incubation period, and R_0 value are likely to vary throughout the course of the epidemic and will depend on local factors influencing transmission, such as demographics, environmental conditions, modeling methodology, and stringency of control measures [16,30].

Epidemic Projections

The projected estimate of daily cases and the final outbreak size were found to depend on the value of R_0 entered in the model [31-33]. The method used to estimate the R_0 value and the time window over which R_0 was calculated both influenced the final projection by a wide margin. The 14-day time window yielded less variable instantaneous R_0 estimates compared to the 7-day time window. We found that the method by Wallinga and Teunis was more sensitive to recent fluctuations in daily case count than the method by Jombart et al in the same time window. Further, per the renewal equation stated earlier, the values of R_0 are most influenced by the trend in daily cases reported within the range of the serial interval (ie, within 5 to 6 days). This model also assumes homogenous mixing, which becomes less applicable with larger populations in which cases emerge from widely separated clusters. Also, the impact of the method of R_0 estimation and the time window was more pronounced when there was a fluctuating trend in cases or when the R_0 value was close to 1. In research settings, R_0 values should be tested through sensitivity analyses by considering variations in time windows and durations and using different methods so that reliable projections can be provided for larger populations [31]. For routine use within program settings at the district level, the method by Jombart et al may be preferable for monitoring the effectiveness of control methods and providing prior R_0 values for projections compared to the method by Wallinga and Teunis and the overall R_0 estimation using the EarlyR package in R.

Our study was based on contact history of infected individuals instead of on daily follow-up of contacts of infected individuals for disease onset. Therefore, we minimized underreporting of longer serial intervals, which may be due to right-truncation in the follow-up method for assessing the serial interval [30].

Further, the use of the time-varying method for daily R_0 estimation and the maximum likelihood method for overall R_0 estimation has the benefit of lower bias compared to the exponential growth and sequential Bayesian methods [34]. It also enables assessment of the effectiveness of control measures on a real-time basis, in contrast to other methods that only provide an aggregate R_0 value [30].

Limitations

One limitation of our study is that population level estimates relying on daily official reports can underestimate the value of R_0 compared to those of closed populations because many infected individuals are likely to be missed, especially if the testing capacity is limited or the proportion of asymptomatic people is high [31]. Further, modeling assumptions such as assuming a finite probability of interaction of infector-infectee pairs reported within a serial interval range may not be applicable for large population cohorts [23]. To overcome these limitations, use of both spatial and temporally structured data has been proposed [35]. The use of contact tracing applications that provide anonymized geolocated data and serial interval estimates could provide more timely and robust epidemiological understanding of emerging diseases such as COVID-19 [36,37].

Conclusions

Public health measures such as testing, contact tracing, and home isolation were found to reduce the instantaneous R_0 value and could thereby reduce the final outbreak size. Instantaneous R_0 estimated using the method proposed by Jombart et al is recommended for guiding COVID-19 response strategy at district level in preference to the method proposed by Wallinga and Teunis and to aggregate R_0 calculation. The final epidemic size was found to be influenced by the R_0 value, which in turn depended on the stringency of control measures. Even a marginal reduction in R_0 as a result of strengthening control measures was found to considerably reduce the projected COVID-19 burden at the district level. Projections based on publicly released daily COVID-19 case data are feasible and could be useful in guiding a data-driven COVID-19 response strategy at a local level. This could be used for both surge capacity planning of the number of hospital beds and ventilators required and for public health responses such as the number of staff required for contact tracing and for provisioning of institutional quarantine or isolation facilities. Therefore, considering the increasing caseload and dynamic situation of COVID-19, a decentralized evidence-driven approach is currently needed.

Acknowledgments

We acknowledge the district administration of Jodhpur for providing the daily COVID-19 case data. We also thankfully acknowledge the staff involved in laboratory diagnosis of COVID-19 and the Master of Public Health scholars at All India Institute of Medical Sciences, Jodhpur, for supporting the epidemiological data collection: Dr Jay Shree Shekhawat, Mr Prasannajeet Bal, Dr Ipsa Kutlehrria, Dr Nainsi Gupta, Dr Neelam Kumari, Dr Mahima Choudhary, Dr Musarrat Siddiqui, Dr Sonali Bhattacharya, Ms Himani, Dr Uplabdh Sahu, Dr. Shubham, Dr Oshi Chaturvedi, Ms Ashu Ranga, Dr Premlata Meghwal, Dr Chunni Lal, Dr Rupali Gupta, Dr Zeba Bano, Dr Diksha Mahajan, Ms Abhilipsa Pradhan, Dr Jinesh Saini, Dr Neha Mantri, and Dr Nishant Soni. The

authors declare that no funding was received from any source for the study or the preparation of this paper. The views expressed in this article are those of the authors alone and do not necessarily represent the views of their organizations.

Authors' Contributions

MKV, VG, and NK collected the data, and SS conducted the analysis. SS wrote the draft manuscript with further input from MKV, VG, AG, MKG, PB, and SM. PB coordinated the data collection process. SM provided overall supervision of the lab testing, clinical care, and research related to COVID-19 at the All India Institute of Medical Sciences, Jodhpur, India. All authors approved the final manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Data used for the serial interval estimation of COVID-19 in Jodhpur, India (103 pairs).

[[XLSX File \(Microsoft Excel File\), 11 KB - publichealth_v6i4e22678_app1.xlsx](#)]

References

1. Weekly epidemiological update for COVID-19 – 21 September 2020. World Health Organization. 2020 Sep 21. URL: https://www.who.int/docs/default-source/coronaviruse/situation-reports/20200921-weekly-epi-update-6.pdf?sfvrsn=d9cf9496_6 [accessed 2020-09-23]
2. Wu J, Leung K, Leung G. Nowcasting and forecasting the potential domestic and international spread of the 2019-nCoV outbreak originating in Wuhan, China: a modelling study. *Lancet* 2020 Feb;395(10225):689-697. [doi: [10.1016/S0140-6736\(20\)30260-9](https://doi.org/10.1016/S0140-6736(20)30260-9)]
3. Alimohamadi Y, Taghdir M, Sepandi M. Estimate of the Basic Reproduction Number for COVID-19: A Systematic Review and Meta-analysis. *J Prev Med Public Health* 2020 May;53(3):151-157 [FREE Full text] [doi: [10.3961/jpmph.20.076](https://doi.org/10.3961/jpmph.20.076)] [Medline: [32498136](https://pubmed.ncbi.nlm.nih.gov/32498136/)]
4. Lv M, Luo X, Estill J, Liu Y, Ren M, Wang J, and on behalf of the COVID-19 evidence and recommendations working group. Coronavirus disease (COVID-19): a scoping review. *Euro Surveill* 2020 Apr;25(15):2000125 [FREE Full text] [doi: [10.2807/1560-7917.ES.2020.25.15.2000125](https://doi.org/10.2807/1560-7917.ES.2020.25.15.2000125)] [Medline: [32317050](https://pubmed.ncbi.nlm.nih.gov/32317050/)]
5. Bulut C, Kato Y. Epidemiology of COVID-19. *Turk J Med Sci* 2020 Apr 21;50(SI-1):563-570 [FREE Full text] [doi: [10.3906/sag-2004-172](https://doi.org/10.3906/sag-2004-172)] [Medline: [32299206](https://pubmed.ncbi.nlm.nih.gov/32299206/)]
6. Revised guidelines for Home Isolation of very mild/pre-symptomatic COVID-19 cases. Ministry of Health and Family Welfare, Government of India. 2020 May 10. URL: <https://www.mohfw.gov.in/pdf/RevisedguidelinesforHomeIsolationofverymildpresymptomaticCOVID19cases10May2020.pdf> [accessed 2020-09-23]
7. Patrikar S, Poojary D, Basannar D, Faujdar D, Kunte R. Projections for novel coronavirus (COVID-19) and evaluation of epidemic response strategies for India. *Med J Armed Forces India* 2020 Jul;76(3):268-275 [FREE Full text] [doi: [10.1016/j.mjafi.2020.05.001](https://doi.org/10.1016/j.mjafi.2020.05.001)] [Medline: [32773928](https://pubmed.ncbi.nlm.nih.gov/32773928/)]
8. Ambikapathy B, Krishnamurthy K. Mathematical Modelling to Assess the Impact of Lockdown on COVID-19 Transmission in India: Model Development and Validation. *JMIR Public Health Surveill* 2020 May 07;6(2):e19368 [FREE Full text] [doi: [10.2196/19368](https://doi.org/10.2196/19368)] [Medline: [32365045](https://pubmed.ncbi.nlm.nih.gov/32365045/)]
9. Kanagarathinam K, Sekar K. Estimation of the reproduction number and early prediction of the COVID-19 outbreak in India using a statistical computing approach. *Epidemiol Health* 2020 May 09;42:e2020028 [FREE Full text] [doi: [10.4178/epih.e2020028](https://doi.org/10.4178/epih.e2020028)] [Medline: [32512670](https://pubmed.ncbi.nlm.nih.gov/32512670/)]
10. Khajanchi S, Sarkar K. Forecasting the daily and cumulative number of cases for the COVID-19 pandemic in India. *Chaos* 2020 Jul;30(7):071101. [doi: [10.1063/5.0016240](https://doi.org/10.1063/5.0016240)] [Medline: [32752627](https://pubmed.ncbi.nlm.nih.gov/32752627/)]
11. Ghosh P, Ghosh R, Chakraborty B. COVID-19 in India: Statewise Analysis and Prediction. *JMIR Public Health Surveill* 2020 Aug 12;6(3):e20341 [FREE Full text] [doi: [10.2196/20341](https://doi.org/10.2196/20341)] [Medline: [32763888](https://pubmed.ncbi.nlm.nih.gov/32763888/)]
12. Mandal S, Bhatnagar T, Arinaminpathy N, Agarwal A, Chowdhury A, Murhekar M, et al. Prudent public health intervention strategies to control the coronavirus disease 2019 transmission in India: A mathematical model-based approach. *Indian J Med Res* 2020;151(2 & 3):190-199 [FREE Full text] [doi: [10.4103/ijmr.IJMR_504_20](https://doi.org/10.4103/ijmr.IJMR_504_20)] [Medline: [32362645](https://pubmed.ncbi.nlm.nih.gov/32362645/)]
13. Bhaskar A, Ponnuraja C, Srinivasan R, Padmanaban S. Distribution and growth rate of COVID-19 outbreak in Tamil Nadu: A log-linear regression approach. *Indian J Public Health* 2020;64(6):188. [doi: [10.4103/ijph.ijph_502_20](https://doi.org/10.4103/ijph.ijph_502_20)]
14. Jodhpur District Census Handbook. Ministry of Home Affairs, Government of India. 2011. URL: https://censusindia.gov.in/2011census/dchb/DCHB_A/08/0815_PART_A_DCHB_JODHPUR.pdf [accessed 2020-09-23]
15. Strategy for COVID-19 Testing in India – Version 5. Indian Council of Medical Research. 2020 May 18. URL: https://www.icmr.gov.in/pdf/covid/strategy/Testing_Strategy_v5_18052020.pdf [accessed 2020-09-03]
16. Delamater PL, Street EJ, Leslie TF, Yang YT, Jacobsen KH. Complexity of the Basic Reproduction Number (R0). *Emerg Infect Dis* 2019 Jan;25(1):1-4 [FREE Full text] [doi: [10.3201/eid2501.171901](https://doi.org/10.3201/eid2501.171901)] [Medline: [30560777](https://pubmed.ncbi.nlm.nih.gov/30560777/)]

17. COVID-19 India. URL: <https://www.covid19india.org/> [accessed 2020-09-03]
18. Jackson C. flexsurv: A Platform for Parametric Survival Modeling in R. *J Stat Softw* 2016 May 12;70:1-33 [FREE Full text] [doi: [10.18637/jss.v070.i08](https://doi.org/10.18637/jss.v070.i08)] [Medline: [29593450](https://pubmed.ncbi.nlm.nih.gov/29593450/)]
19. Jombart T, Nouvellet P, Bhatia S, Kamvar Z, Taylor T, Ghazzi S. Projections: Project future case incidence. R Project. 2018. URL: <https://cran.r-project.org/web/packages/projections/index.html> [accessed 2020-09-23]
20. Jombart T, Cori A, Nouvellet P. earlyR: Estimation of Transmissibility in the Early Stages of a Disease Outbreak. R Project. 2017. URL: <https://cran.r-project.org/web/packages/earlyR/index.html> [accessed 2020-09-23]
21. Cori A, Cauchemez S, Ferguson NM, Fraser C, Dahlqvist E, Demarsh PA, et al. EpiEstim: Estimate Time Varying Reproduction Numbers from Epidemic Curves. R Project. URL: <https://cran.r-project.org/web/packages/EpiEstim/index.html> [accessed 2020-09-03]
22. Nouvellet P, Cori A, Garske T, Blake IM, Dorigatti I, Hinsley W, et al. A simple approach to measure transmissibility and forecast incidence. *Epidemics* 2018 Mar;22:29-35 [FREE Full text] [doi: [10.1016/j.epidem.2017.02.012](https://doi.org/10.1016/j.epidem.2017.02.012)] [Medline: [28351674](https://pubmed.ncbi.nlm.nih.gov/28351674/)]
23. Wallinga J, Teunis P. Different epidemic curves for severe acute respiratory syndrome reveal similar impacts of control measures. *Am J Epidemiol* 2004 Sep 15;160(6):509-516 [FREE Full text] [doi: [10.1093/aje/kwh255](https://doi.org/10.1093/aje/kwh255)] [Medline: [15353409](https://pubmed.ncbi.nlm.nih.gov/15353409/)]
24. Sjödin H, Wilder-Smith A, Osman S, Farooq Z, Rocklöv J. Only strict quarantine measures can curb the coronavirus disease (COVID-19) outbreak in Italy, 2020. *Euro Surveill* 2020 Apr 02;25(13):2000280. [doi: [10.2807/1560-7917.es.2020.25.13.2000280](https://doi.org/10.2807/1560-7917.es.2020.25.13.2000280)]
25. Park M, Cook AR, Lim JT, Sun Y, Dickens BL. A Systematic Review of COVID-19 Epidemiology Based on Current Evidence. *J Clin Med* 2020 Mar 31;9(4):967 [FREE Full text] [doi: [10.3390/jcm9040967](https://doi.org/10.3390/jcm9040967)] [Medline: [32244365](https://pubmed.ncbi.nlm.nih.gov/32244365/)]
26. Zhang P, Wang T, Xie S. Meta-analysis of several epidemic characteristics of COVID-19. medRxiv. Preprint posted online on June 3 2020 [FREE Full text] [doi: [10.1101/2020.05.31.20118448](https://doi.org/10.1101/2020.05.31.20118448)] [Medline: [32577693](https://pubmed.ncbi.nlm.nih.gov/32577693/)]
27. Najafi F, Izadi N, Hashemi-Nazari S, Khosravi-Shadmani F, Nikbakht R, Shakiba E. Serial interval and time-varying reproduction number estimation for COVID-19 in western Iran. *New Microbes New Infect* 2020 Jul;36:100715 [FREE Full text] [doi: [10.1016/j.nmni.2020.100715](https://doi.org/10.1016/j.nmni.2020.100715)] [Medline: [32566233](https://pubmed.ncbi.nlm.nih.gov/32566233/)]
28. Liu Y, Gayle AA, Wilder-Smith A, Rocklöv J. The reproductive number of COVID-19 is higher compared to SARS coronavirus. *J Travel Med* 2020 Mar 13;27(2) [FREE Full text] [doi: [10.1093/jtm/taaa021](https://doi.org/10.1093/jtm/taaa021)] [Medline: [32052846](https://pubmed.ncbi.nlm.nih.gov/32052846/)]
29. Khosravi A, Chaman R, Rohani-Rasaf M, Zare F, Mehravaran S, Emamian M. The basic reproduction number and prediction of the epidemic size of the novel coronavirus (COVID-19) in Shahroud, Iran. *Epidemiol Infect* 2020 Jun 10;148:e115 [FREE Full text] [doi: [10.1017/S0950268820001247](https://doi.org/10.1017/S0950268820001247)] [Medline: [32517845](https://pubmed.ncbi.nlm.nih.gov/32517845/)]
30. Aghaali M, Kolifarhood G, Nikbakht R, Saadati HM, Hashemi Nazari SS. Estimation of the serial interval and basic reproduction number of COVID-19 in Qom, Iran, and three other countries: A data-driven analysis in the early phase of the outbreak. *Transbound Emerg Dis* 2020 May 30 [FREE Full text] [doi: [10.1111/tbed.13656](https://doi.org/10.1111/tbed.13656)] [Medline: [32473049](https://pubmed.ncbi.nlm.nih.gov/32473049/)]
31. Rocklöv J, Sjödin H, Wilder-Smith A. COVID-19 outbreak on the Diamond Princess cruise ship: estimating the epidemic potential and effectiveness of public health countermeasures. *J Travel Med* 2020 May 18;27(3):e [FREE Full text] [doi: [10.1093/jtm/taaa030](https://doi.org/10.1093/jtm/taaa030)] [Medline: [32109273](https://pubmed.ncbi.nlm.nih.gov/32109273/)]
32. Zhang S, Diao M, Yu W, Pei L, Lin Z, Chen D. Estimation of the reproductive number of novel coronavirus (COVID-19) and the probable outbreak size on the Diamond Princess cruise ship: A data-driven analysis. *Int J Infect Dis* 2020 Apr;93:201-204 [FREE Full text] [doi: [10.1016/j.ijid.2020.02.033](https://doi.org/10.1016/j.ijid.2020.02.033)] [Medline: [32097725](https://pubmed.ncbi.nlm.nih.gov/32097725/)]
33. Tildesley MJ, Keeling MJ. Is R(0) a good predictor of final epidemic size: foot-and-mouth disease in the UK. *J Theor Biol* 2009 Jun 21;258(4):623-629 [FREE Full text] [doi: [10.1016/j.jtbi.2009.02.019](https://doi.org/10.1016/j.jtbi.2009.02.019)] [Medline: [19269297](https://pubmed.ncbi.nlm.nih.gov/19269297/)]
34. Obadia T, Haneef R, Boëlle PY. The R0 package: a toolbox to estimate reproduction numbers for epidemic outbreaks. *BMC Med Inform Decis Mak* 2012 Dec 18;12(1):147 [FREE Full text] [doi: [10.1186/1472-6947-12-147](https://doi.org/10.1186/1472-6947-12-147)] [Medline: [23249562](https://pubmed.ncbi.nlm.nih.gov/23249562/)]
35. Ng T, Wen T. Spatially Adjusted Time-varying Reproductive Numbers: Understanding the Geographical Expansion of Urban Dengue Outbreaks. *Sci Rep* 2019 Dec 16;9(1):19172 [FREE Full text] [doi: [10.1038/s41598-019-55574-0](https://doi.org/10.1038/s41598-019-55574-0)] [Medline: [31844099](https://pubmed.ncbi.nlm.nih.gov/31844099/)]
36. Li J, Guo X. Global Deployment Mappings and Challenges of Contact-tracing Apps for COVID-19. SSRN. Preprint posted online on May 26 2020. [doi: [10.2139/ssrn.3609516](https://doi.org/10.2139/ssrn.3609516)]
37. Davalbhakta S, Advani S, Kumar S, Agarwal V, Bhojar S, Fedirko E, et al. A Systematic Review of Smartphone Applications Available for Corona Virus Disease 2019 (COVID19) and the Assessment of their Quality Using the Mobile Application Rating Scale (MARS). *J Med Syst* 2020 Aug 10;44(9):164 [FREE Full text] [doi: [10.1007/s10916-020-01633-3](https://doi.org/10.1007/s10916-020-01633-3)] [Medline: [32779002](https://pubmed.ncbi.nlm.nih.gov/32779002/)]

Abbreviations

AIC: Akaike information criterion

R₀: basic reproduction number

rRT-PCR: real-time reverse transcription–polymerase chain reaction

Edited by T Sanchez; submitted 21.07.20; peer-reviewed by J Li, N Mohammad Gholi Mezerji; comments to author 13.08.20; revised version received 18.08.20; accepted 09.09.20; published 15.10.20.

Please cite as:

Saurabh S, Verma MK, Gautam V, Kumar N, Goel AD, Gupta MK, Bhardwaj P, Misra S

Transmission Dynamics of the COVID-19 Epidemic at the District Level in India: Prospective Observational Study

JMIR Public Health Surveill 2020;6(4):e22678

URL: <http://publichealth.jmir.org/2020/4/e22678/>

doi: [10.2196/22678](https://doi.org/10.2196/22678)

PMID: [33001839](https://pubmed.ncbi.nlm.nih.gov/33001839/)

©Suman Saurabh, Mahendra Kumar Verma, Vaishali Gautam, Nitesh Kumar, Akhil Dhanesh Goel, Manoj Kumar Gupta, Pankaj Bhardwaj, Sanjeev Misra. Originally published in JMIR Public Health and Surveillance (<http://publichealth.jmir.org>), 15.10.2020. This is an open-access article distributed under the terms of the Creative Commons Attribution License (<https://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in JMIR Public Health and Surveillance, is properly cited. The complete bibliographic information, a link to the original publication on <http://publichealth.jmir.org>, as well as this copyright and license information must be included.

Original Paper

The Resurgence of Cyber Racism During the COVID-19 Pandemic and its Aftereffects: Analysis of Sentiments and Emotions in Tweets

Akash Dutt Dubey¹, PhD

Jaipuria Institute of Management, Jaipur, India

Corresponding Author:

Akash Dutt Dubey, PhD

Jaipuria Institute of Management

Pratap Nagar, Sanganer

Jaipur, 302017

India

Phone: +91 7510099112

Email: drakashddubey@gmail.com

Abstract

Background: With increasing numbers of patients with COVID-19 globally, China and the World Health Organization have been blamed by some for the spread of this disease. Consequently, instances of racism and hateful acts have been reported around the world. When US President Donald Trump used the term “Chinese Virus,” this issue gained momentum, and ethnic Asians are now being targeted. The online situation looks similar, with increases in hateful comments and posts.

Objective: The aim of this paper is to analyze the increasing instances of cyber racism during the COVID-19 pandemic, by assessing emotions and sentiments associated with tweets on Twitter.

Methods: In total, 16,000 tweets from April 11-16, 2020, were analyzed to determine their associated sentiments and emotions. Statistical analysis was carried out using R. Twitter API and the sentimentr package were used to collect tweets and then evaluate their sentiments, respectively. This research analyzed the emotions and sentiments associated with terms like “Chinese Virus,” “Wuhan Virus,” and “Chinese Corona Virus.”

Results: The results suggest that the majority of the analyzed tweets were of negative sentiment and carried emotions of fear, sadness, anger, and disgust. There was a high usage of slurs and profane words. In addition, terms like “China Lied People Died,” “Wuhan Health Organization,” “Kung Flu,” “China Must Pay,” and “CCP is Terrorist” were frequently used in these tweets.

Conclusions: This study provides insight into the rise in cyber racism seen on Twitter. Based on the findings, it can be concluded that a substantial number of users are tweeting with mostly negative sentiments toward ethnic Asians, China, and the World Health Organization.

(*JMIR Public Health Surveill* 2020;6(4):e19833) doi:[10.2196/19833](https://doi.org/10.2196/19833)

KEYWORDS

COVID-19; pandemic; China; racism; WHO; Twitter; infodemiology; infodemic

Introduction

Since their inception, social media networks have served as platforms where people worldwide can express their views and opinions. In 1993, The New Yorker [1] had published a cartoon, titled “On the Internet, nobody knows you're a dog,” signifying that caste, race, ethnicity, religion, and appearance do not matter when you are on the internet. In contrast, Nakamura [2] denied the existence of this utopian model and suggested that the internet is “an outstanding example of a racist medium.” Brown [3] has concluded that the internet has often been a place where

racism is disseminated in various ways, including through certain websites. These websites used offensive stereotypes to establish white supremacy over the ethnic peoples of Africa. In 2011, Clark et al [4] analyzed weblogs using modified consensual qualitative research to study different types of racial microaggression targeted at Native Americans. There have been sufficient studies that have verified the presence of racial aggression and hatred toward different races, ethnicities, and religions on the internet.

At present, the world is facing the brunt of COVID-19. COVID-19 infections were first reported in December 2019, when cases of a severe respiratory infection was observed in several patients from Wuhan, Hubei Province. These patients worked in a wholesale fish and seafood market (known as wet markets) [5]. In January 2020, the markets were closed down, and disinfectants were used to sanitize them. On January 7, 2020, researchers isolated a novel coronavirus, now referred to as SARS-CoV-2. Initially, the World Health Organization (WHO) denied the possibility of human-to-human transmission of SARS-CoV-2 on January 11, 2020. However, confirmed cases continued to soar, and on January 30, 2020, the World Health Organization declared COVID-19 a Public Health Emergency of International Concern (PHEIC) and an epidemic. Finally, on March 11, 2020, the WHO declared COVID-19 as a pandemic. Due to the lack of any specific treatments, the WHO recommended self-isolation and lockdown to reduce the spread of COVID-19.

On March 17, 2020, US President Donald Trump posted the following tweet: “The United States will be powerfully supporting those industries, like Airlines and others, that are particularly affected by the Chinese Virus. We will be stronger than ever before!” [6]. The term “Chinese Virus” sparked a series of controversies; hashtags like #ChineseVirus and #WuhanVirus started trending among supporters of Donald Trump [7-9] on various online social networking platforms, with Twitter being the most prominent of them. Racial slurs and profane words against Asian communities have been visible on Twitter ever since [10,11]. In Italy, there have been several reports of anti-Chinese racism and discrimination. It is also believed that the increasing rate of xenophobia in Italy was the result of the circulation of information related to racism [12]. According to Budhwani and Sun [13], there has been a 10-fold increase in the usage of words like “China Virus” and “Chinese Virus.”

This research was conducted keeping in mind that there has been an increase in cyber racism and online displays of hatred during the COVID-19 pandemic. The main aim of this research is to analyze the sentiments and emotions associated with the tweets that mention “Chinese Virus” or “Wuhan Virus.” This research also analyzed the most frequently used words in these tweets.

Methods

Twitter, one of the world’s most popular microblogging service providers, was launched in 2006. The estimated number of Twitter users is 330 million worldwide. Initially, tweets were limited to 140 characters, but this was later increased to 280 characters. Twitter has been often used as a platform where people disseminate information, as well as share their opinion and emotions. This rapid sharing of opinions enables researchers to determine the sentiments associated with almost everything

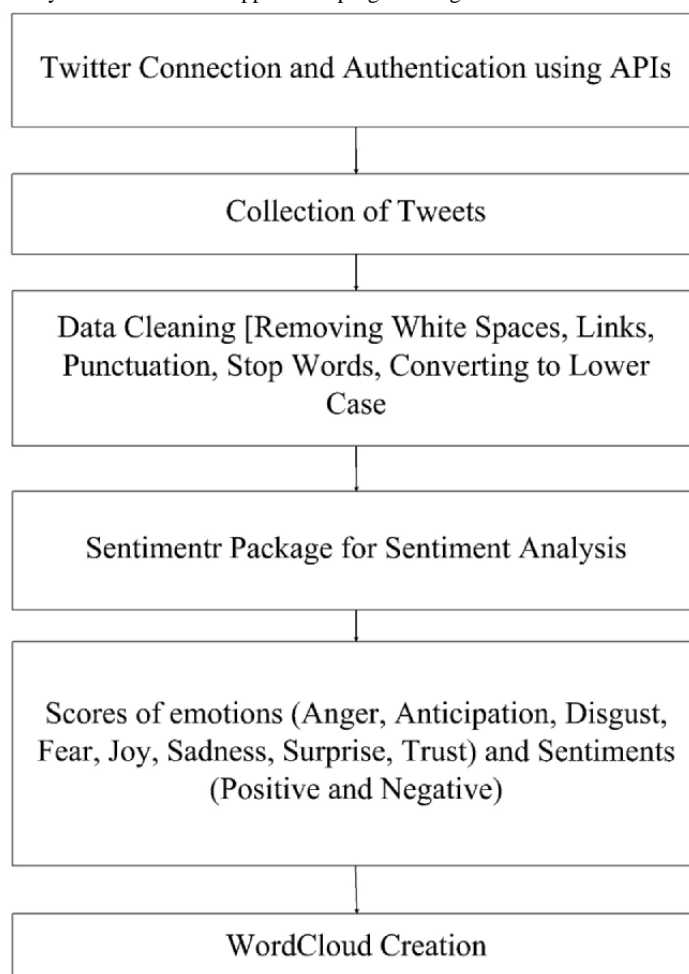
(eg, sentiments toward products, movies, politics, digital technology, and natural calamities) [14-18].

Sentiment analysis of tweets has also been used to determine the general population’s perspective on different diseases. Sentiment analysis of Twitter posts has been carried out to study the topic coverage and sentiments regarding the Ebola virus [19]. This study separately analyzed two media sources (ie, Twitter and news sources). Similarly, a study was conducted to examine the key topics that influenced negative sentiments on Twitter regarding the Zika virus [20]. Sentiment analysis was also done to analyze tweets by patients who were affected by Crohn disease, to gain an understanding of their perspective on a specific medical therapy [21].

While there is no single accepted psychological theory of basic human emotions, most studies accept the theory that a simple positive-negative dichotomy cannot be used to categorize human emotions as a whole. On the same lines, it is believed that the automatic sentiment analysis must also implement finely tuned algorithms to detail human emotions. Sentimentr (CRAN) is one such package that tries to evaluate the sentiments and emotions associated with texts [22]. The sentimentr package has been successfully used in analyzing the sentiments of tweets on migraine activity [23]. It has been also used to analyze the tweets of Donald Trump to examine the relation between tweet sentiment and the number of retweets [24]. In a review of four different sentiment computation packages, Naldi [25] concluded that the critical issue of negators is accurately dealt in the sentimentr package. In other words, sentimentr was accurate in calculating the difference between words like “useful,” “not useful” (negator), “really useful” (amplifier), and “hardly useful” (deamplifier). The potential of this package to calculate the sentiments based on the role of negators, amplifiers, and deamplifiers was the reason this package was used to analyze tweet sentiments in this study.

Figure 1 illustrates the flowchart for this study’s sentiment and emotion analysis of tweets. The tweets were collected by using rtweet package in R (The R Foundation). To collect tweets, the *search_tweets* function of rtweet was used. The following keywords were used to fetch tweets during the collection process: #ChineseVirus, #ChineseVirusCorona, and #WuhanVirus. The date range of the search was set to April 11-16, 2020. The search process did not collect retweets and replies, so that the duplication of data can be avoided.

After the tweets were collected, the data cleaning process was performed using the Text Mining package in R. This package was used to remove white space, punctuation, stop words, and the tweets were converted to lower case. After data cleaning, the sentimentr package was applied to analyze the tweets. Once the scoring of the tweets was done on the basis of sentiments and emotions, the terms related to positive and negative sentiments, profanity, and emotions were also calculated for further analysis.

Figure 1. Flowchart for sentiment analysis of tweets. API: application programming interface.

Results

Using the tweet collection process, a total of 16,000 tweets were collected for the analysis. The collected tweets were analyzed using the sentimentr package in R, and the scoring was done on the basis of positive and negative sentiments. The sentimentr package scores sentiments on a scale where 0 is considered neutral, negative numbers indicate the presence of negative sentiments, and positive numbers indicate the presence of positive sentiments. The sentiment score of each tweet was calculated individually and then the complete report of the sentiment across all tweets was generated.

The minimum value obtained in the analysis is -1.930 , which is the score of the tweet with the most negative sentiment. The maximum score obtained during the analysis is 5.371 (ie, the most positive tweet). The median and mean of the sentiments

are -0.016 and -0.063 , respectively. This shows that the sentiments observed in the tweets have a negative skew, that is, the number of tweets with negative sentiments were more prevalent than the number of positive sentiments.

Table 1 shows the emotion analysis of the collected tweets. While the sentiment analysis of the tweets provide an overview of how people were tweeting, the emotion analysis provides insight into why this was happening. It can be seen that tweets expressing fear are almost equal in prevalence to the tweets related to trust. When the four negative emotions (fear, sadness, anger, and disgust) were analyzed collectively, they comprised 52.18% ($n=8450$) of the sample. While this result confirms the presence of primarily negative sentiments in the tweets sampled, it also discloses the constituents of the negative sentiments in the tweets. Sample tweets expressing different emotions are shown in Table 2.

Table 1. Emotion analysis of tweets.

Emotion	Tweets, n (%)
Trust	2926 (18.29)
Fear	2857 (17.86)
Sadness	2123 (13.27)
Anticipation	2005 (12.53)
Anger	1972 (12.32)
Disgust	1498 (9.36)
Joy	1422 (8.89)
Surprise	1198 (7.49)

Table 2. Sample tweets with different emotions.

Emotion	Tweet
Trust	<ul style="list-style-type: none"> • “CMgovt has done very good job to handle #WuhanVirus problem in state” • “Breaking News US Government gave Wuhan Virology lab aMillion grant for virus research #CoronaVirusUpdate #Coronavirus #COVID #Covid #WuhanVirus #BreakingNews” • “Great now Biden needs to explain that him calling the Chinese travel ban xenophobic would NEVER happen again and he made a HUGE mistake cause this attitude would kill us all if he was president #ChineseVirusCorona”
Anger	<ul style="list-style-type: none"> • “Good for Trump Calling the virus what it is the Wuhan virus Dont know why it triggers you so badly but you always have to find something daily to bang Trump around It gets old and you look childish #WuhanVirus #WuhanFlu” • “Chinas carelessness and deceit has crashed global economies and costed countries trillions of dollars Every cent of debt that they hold from other countries should be forgiven Coronavirus #WuhanVirus #ChinaLiedPeopleDied” • “I guess Twitter should ban all the Chinese because its ban in China #ChinaLiedPeopleDied #ChineseVirus”
Sadness	<ul style="list-style-type: none"> • “Sir we had great hopes with you but it all shattered into pieces You r siding with the evil of CCP in this difficult timeshas become a mouthpiece for communist chinafunding it would be a crime against humanity #ChineseVirus” • “Just look at the economic destruction the #WuhanVirus has inflicted on the American ppl” • “#ChineseVirus COVID We lost th member of familyfriend in the CoronaWarfound ve hospitalised Yesterday world heard news of a mths old corona infected baby I plead to my friendsfollowers Corona is a seriousreal #KeepSocialDistancing #StayHome-SaveLives”
Anticipation	<ul style="list-style-type: none"> • “Considering most of the vaccines across globe come from India India might play a vital role in discovery of vaccine on #ChineseVirus #VaccinesSaveLives” • “Our life is going to be changed drasticallyBe prepared for it#ChineseVirus” • “I KNEW IT I think all countries should declare war on China WHO #ChinaLiedPeopleDie #Wuhan #ChineseVirus #ChinaMustPay #ChinaVsTheWorld”
Fear	<ul style="list-style-type: none"> • “We are heading for a long haul I am afraid in this fight against #ChineseVirus with this pandering to a community which was not supposed to be in India since” • “We are afraid of #ChineseVirus so we are retreating now” • “Sorry i afraid of #ChineseVirusCorona #ChineseVirus”
Disgust	<ul style="list-style-type: none"> • “Will you be so shameless to buy Chinese mobile phones after #ChinaVirus #ChineseVirusCorona #coronavirusindia #coronavirus #COVID #covidindia Hit China hard where it will pain them most PS A branded phone fetches Chinese company more profit than selling components” • “Shame on you #ChineseVirusCorona” • “Shameful the very same people who caused the #WuhanVirus pandemic is now discriminating against innocent Africans”
Joy	<ul style="list-style-type: none"> • “Happy Thai New Year Buddy Lets fight together #MilkTeaAlliance #FightForFreedom #StandwithHK #hkisnotchina #TaiwanIsaCountry nnevvy #ChineseVirus #ChinaMustPay #ChinaLiedAndPeopleDied” • “Not only recovered but got raised big fundLovely D coronavirus #ChineseVirus #WuhanVirus” • “I get enough to live comfortably This #ChineseVirus just depleted my savings Im happy with my investment”
Surprise	<ul style="list-style-type: none"> • “Am surprised we still trust China havent we learnt our lesson #ChineseVirus” • “Shocking Did you know your taxwere being spent on this So is NIH partially responsible for #WuhanVirus” • “The world is still in utter shock. Right from the start experts advised the president to refrain from labelling COVIDa #ChineseVirus to no avail It appears whatever DonaldJTrump was harboring against China has finally started manifesting in life threatening developments”

While analyzing the tweets, the 15 most frequent words conveying different emotions were also analyzed. The results of the analysis are illustrated in [Table 3](#). Words like death, good, money, pay, pandemic, Trump, and organization were most frequently used by people while mentioning terms like “ChineseVirus,” “WuhanVirus,” and “ChineseVirusCorona.”

The presence of words like death, pay, pandemic, evil, and disease were repeatedly used in the tweets associated with negative sentiments and emotions. These results, combined with [Table 3](#) and the statistics presented earlier, reflect the negative sentiments and emotions that have been communicated online.

Table 3. Frequency of the most used terms in the analyzed tweets.

Term	Tweets, n (%)
Death	1656 (13.51)
Good	1352 (11.03)
Money	1305 (10.65)
Pay	1284 (10.48)
Pandemic	1254 (10.23)
Trump	824 (6.72)
Organization	668 (5.45)
Hope	588 (4.80)
God	536 (4.37)
Time	513 (4.19)
Evil	472 (3.85)
Bad	472 (3.85)
Fight	470 (3.83)
Medical	447 (3.65)
Disease	416 (3.39)

Discussion

Principal Findings

Based on the results obtained in the analysis, the negative sentiments and emotions associated with the collected tweets are evident. A good number of tweets including the term “Chinese Virus” expressed hatred, disgust, fear, and anger. Apart from the words that were associated with different emotions, there were some slang words or constructions created by users that were not detected by the sentimentr package. Prominent among those were “ccpisterrorist,” “ccpliedpeopledied,” “ccpvirus,” “ccpviruscoronavirus,” “chinaliedpeopledied,” “chinamustexplain,” “chinamustpay,” “chinesebioterrorism,” “kungflu,” “makechinapay,” “milkteaalliance,” “wholiedpeopledied,” “wuhanhealthorganisation.” The “ccp” in these terms refers to the Chinese Communist Party, the ruling party of China headed by Xi Jinping, the President of the People’s Republic of China. Some of these terms also expressed anger toward the WHO, calling it “Wuhan Health Organization.” This trend suggests that both China and the WHO are being held responsible for the spread of COVID-19.

Prominent words like virus, Trump, pandemic, government, outbreak, pay, communist, propaganda, blame, killed, shame, killing, shit, hell, stupid, lying, lies, die, etc, were used to reflect negative sentiments in tweets, while words like right, like, good, money, accountable, humanity, responsible, work, organization, great, better, well, global, please, thanks, etc, were used to

indicate positive sentiments in tweets. During the analysis, terms categorized as profanity were also analyzed, and a frequent usage of profane words in tweets was observed. This list includes fuck, shit, hell, fucking, ass, crap, screw, fucks, bastards, bitch, bastard, Nazis, ahole, and nazi. These words reflect the disgust-related emotions in tweets.

Overall, based on the findings of this paper, it can be clearly stated that the sentiments of people tweeting about the so-called “Chinese Virus” have been mostly negative. The use of negative words, combined with a good dosage of profane terms, reflect the emotions of tweets, which are mainly concentrated toward a sense of fear, sadness, anger, and disgust. The results also indicate signs of discrimination and racism in the COVID-19 era, which has been previously shown by Coates [26]. The results obtained in this study further strengthen the fact that there has been a substantial increase in cyber racism due to COVID-19.

Conclusion and Future Works

In this paper, tweets were analyzed to evaluate the level of cyber racism encountered during the COVID-19 pandemic. For this purpose, tweets were collected if they mentioned “ChineseVirus,” “WuhanVirus,” or “ChineseVirusCorona.” This work demonstrates that the sentiments of a majority of the tweets were negative. Further analysis of emotions associated with the tweets also revealed that there was a sense of fear, anger, and disgust among Twitter users. Additionally, there were also slang terms that expressed negative sentiments toward

China, Wuhan, and the WHO. The majority of the terms used in the tweets were negative and included death, pay, communist, ccp, racist, etc. The study also revealed a substantial use of profane words, which supports the conclusion that cyber racism

has been increasing during the COVID-19 pandemic. Future studies can build on this study by analyzing trends of cyber racism in the coming days.

Conflicts of Interest

None declared.

References

- Steiner P. On the Internet, nobody knows you're a dog. *The New Yorker* 1993;69(20):61-61.
- Nakamura L. Digitizing race: visual cultures of the Internet. *Choice Reviews Online* 2008 Aug 01;45(12):45-6837. [doi: [10.5860/choice.45-6837](https://doi.org/10.5860/choice.45-6837)]
- Brown C. www.hate.com: White Supremacist Discourse on the Internet and the Construction of Whiteness Ideology. *Howard Journal of Communications* 2009 May 05;20(2):189-208. [doi: [10.1080/10646170902869544](https://doi.org/10.1080/10646170902869544)]
- Clark DA, Spanierman LB, Reed TD, Soble JR, Cabana S. Documenting Weblog expressions of racial microaggressions that target American Indians. *Journal of Diversity in Higher Education* 2011;4(1):39-50. [doi: [10.1037/a0021762](https://doi.org/10.1037/a0021762)]
- Huang C, Wang Y, Li X, Ren L, Zhao J, Hu Y, et al. Clinical features of patients infected with 2019 novel coronavirus in Wuhan, China. *The Lancet* 2020 Feb;395(10223):497-506. [doi: [10.1016/s0140-6736\(20\)30183-5](https://doi.org/10.1016/s0140-6736(20)30183-5)]
- Trump D. The United States will be powerfully supporting those industries...We will be stronger than ever before!. Twitter. 2020. URL: <https://twitter.com/realDonaldTrump/status/1239685852093169664> [accessed 2020-05-03]
- Tavernise S, Oppel Jr. RA. Spit On, Yelled At, Attacked: Chinese-Americans Fear for Their Safety. *The New York Times*. 2020 Mar 23. URL: <https://www.nytimes.com/2020/03/23/us/chinese-coronavirus-racist-attacks.html> [accessed 2020-05-03]
- Aratani L. 'Coughing while Asian': living in fear as racism feeds off coronavirus panic. *The Guardian*. 2020 Mar 24. URL: <https://www.theguardian.com/world/2020/mar/24/coronavirus-us-asian-americans-racism> [accessed 2020-03-05]
- Scott D. Trump's new fixation on using a racist name for the coronavirus is dangerous. *Vox*. 2020 Mar 18. URL: <https://www.vox.com/2020/3/18/21185478/coronavirus-usa-trump-chinese-virus> [accessed 2020-05-03]
- Zheng Y, Goh E, Wen J. The effects of misleading media reports about COVID-19 on Chinese tourists' mental health: a perspective article. *Anatolia* 2020 Mar 28;31(2):337-340. [doi: [10.1080/13032917.2020.1747208](https://doi.org/10.1080/13032917.2020.1747208)]
- Zhu H. Countering COVID-19-related anti-Chinese racism with translanguaged swearing on social media. *Ahead-of-print. Multilingua* 2020 Aug 24;39(5):607-616 [FREE Full text] [doi: [10.1515/multi-2020-0093](https://doi.org/10.1515/multi-2020-0093)]
- Rovetta A, Bhagavathula AS. COVID-19-Related Web Search Behaviors and Infodemic Attitudes in Italy: Infodemiological Study. *JMIR Public Health Surveill* 2020 May 05;6(2):e19374 [FREE Full text] [doi: [10.2196/19374](https://doi.org/10.2196/19374)] [Medline: [32338613](https://pubmed.ncbi.nlm.nih.gov/32338613/)]
- Budhwani H, Sun R. Creating COVID-19 Stigma by Referencing the Novel Coronavirus as the "Chinese virus" on Twitter: Quantitative Analysis of Social Media Data. *J Med Internet Res* 2020 May 06;22(5):e19301 [FREE Full text] [doi: [10.2196/19301](https://doi.org/10.2196/19301)] [Medline: [32343669](https://pubmed.ncbi.nlm.nih.gov/32343669/)]
- Shirsat V, Jagdale R, Shende K, Deshmukh SN, Kawale S. Sentence Level Sentiment Analysis from News Articles and Blogs using Machine Learning Techniques. *ijcse* 2019 May 31;7(5):1-6. [doi: [10.26438/ijcse/v7i5.16](https://doi.org/10.26438/ijcse/v7i5.16)]
- Uma Ramya V, Thirupathi Rao K. Sentiment Analysis of Movie Review using Machine Learning Techniques. *IJET* 2018 Mar 18;7(2.7):676. [doi: [10.14419/ijet.v7i2.7.10921](https://doi.org/10.14419/ijet.v7i2.7.10921)]
- M A, Ravikumar P. Survey: Twitter data Analysis using Opinion Mining. *IJCA* 2015 Oct 15;128(5):34-36. [doi: [10.5120/ijca2015906553](https://doi.org/10.5120/ijca2015906553)]
- Maindola P, Singhal N, Dubey A. Sentiment Analysis of Digital Wallets and UPI Systems in India Post Demonetization Using IBM Watson. Chennai: IEEE; 2018 Presented at: 2018 International Conference on Computer Communication and Informatics (ICCCI); Jan 4-6, 2018; Coimbatore, India p. 1-6 URL: <https://ieeexplore.ieee.org/document/8441441> [doi: [10.1109/iccci.2018.8441441](https://doi.org/10.1109/iccci.2018.8441441)]
- Wang Y, Taylor JE. Coupling sentiment and human mobility in natural disasters: a Twitter-based study of the 2014 South Napa Earthquake. *Nat Hazards* 2018 Mar 15;92(2):907-925. [doi: [10.1007/s11069-018-3231-1](https://doi.org/10.1007/s11069-018-3231-1)]
- Kim EH, Jeong YK, Kim Y, Kang KY, Song M. Topic-based content and sentiment analysis of Ebola virus on Twitter and in the news. *Journal of Information Science* 2016 Jul 11;42(6):763-781. [doi: [10.1177/0165551515608733](https://doi.org/10.1177/0165551515608733)]
- Mamidi R, Miller M, Banerjee T, Romine W, Sheth A. Identifying Key Topics Bearing Negative Sentiment on Twitter: Insights Concerning the 2015-2016 Zika Epidemic. *JMIR Public Health Surveill* 2019 Jun 04;5(2):e11036 [FREE Full text] [doi: [10.2196/11036](https://doi.org/10.2196/11036)] [Medline: [31165711](https://pubmed.ncbi.nlm.nih.gov/31165711/)]
- Rocchetti M, Marfia G, Salomoni P, Prandi C, Zagari RM, Gningaye Kengni FL, et al. Attitudes of Crohn's Disease Patients: Infodemiology Case Study and Sentiment Analysis of Facebook and Twitter Posts. *JMIR Public Health Surveill* 2017 Aug 09;3(3):e51 [FREE Full text] [doi: [10.2196/publichealth.7004](https://doi.org/10.2196/publichealth.7004)] [Medline: [28793981](https://pubmed.ncbi.nlm.nih.gov/28793981/)]
- Rinker T. Calculate Text Polarity Sentiment [R package sentimentr version 2.7.1]. Cran.r-project.org. 2019. URL: <https://cran.r-project.org/package=sentimentr> [accessed 2020-05-03]

23. Deng H, Wang Q, Turner D, Sexton K, Burns S, Eikermann M, et al. Sentiment analysis of real-world migraine tweets for population research. *Cephalalgia Reports* 2020 Jan 15;3(3):1-9. [doi: [10.1177/2515816319898867](https://doi.org/10.1177/2515816319898867)]
24. Ouyang Y, Waterman RW. Trump Tweets: A Text Sentiment Analysis. In: *Trump, Twitter, and the American Democracy*. UK: Palgrave Macmillan, Cham; 2020:89-129.
25. Naldi M. A review of sentiment computation methods with R packages. Preprint. arXiv 2019 Jan 24:e [\[FREE Full text\]](#)
26. Coates M. Covid-19 and the rise of racism. *BMJ* 2020 Apr 06;369:m1384. [doi: [10.1136/bmj.m1384](https://doi.org/10.1136/bmj.m1384)] [Medline: [32253178](#)]

Abbreviations

PHEIC: Public Health Emergency of International Concern

WHO: World Health Organization

Edited by G Eysenbach; submitted 03.05.20; peer-reviewed by H Budhwani, E Bellei, M Alam; comments to author 15.05.20; revised version received 27.05.20; accepted 14.09.20; published 15.10.20.

Please cite as:

Dubey AD

The Resurgence of Cyber Racism During the COVID-19 Pandemic and its Aftereffects: Analysis of Sentiments and Emotions in Tweets
JMIR Public Health Surveill 2020;6(4):e19833

URL: <http://publichealth.jmir.org/2020/4/e19833/>

doi: [10.2196/19833](https://doi.org/10.2196/19833)

PMID: [32936772](https://pubmed.ncbi.nlm.nih.gov/32936772/)

©Akash Dutt Dubey. Originally published in *JMIR Public Health and Surveillance* (<http://publichealth.jmir.org>), 15.10.2020. This is an open-access article distributed under the terms of the Creative Commons Attribution License (<https://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in *JMIR Public Health and Surveillance*, is properly cited. The complete bibliographic information, a link to the original publication on <http://publichealth.jmir.org>, as well as this copyright and license information must be included.

Original Paper

Deployment of a Smart Handwashing Station in a School Setting During the COVID-19 Pandemic: Field Study

Jeremy Herbert^{1*}, PhD; Caitlin Horsham^{2*}, MSc; Helen Ford², MSc; Alexander Wall¹, Grad Dip; Elke Hacker², PhD

¹Designworks Group Pty Ltd, Brisbane, Australia

²School of Public Health and Social Work, Queensland University of Technology, Brisbane, Australia

*these authors contributed equally

Corresponding Author:

Elke Hacker, PhD

School of Public Health and Social Work

Queensland University of Technology

60 Musk Avenue

Brisbane, 4059

Australia

Phone: 61 0731389674

Email: elke.hacker@qut.edu.au

Abstract

Background: Hand hygiene is one of the most effective ways to remove germs, prevent the spread of infectious pathogens, and avoid getting sick. Since the COVID-19 pandemic began, health authorities have been advocating good hand hygiene practices.

Objective: The primary aim of this study is to field test a prototype smart handwashing station deployed in a school setting during the COVID-19 pandemic.

Methods: We deployed a smart handwashing station and examined key technological considerations including connectivity, security, and data management systems, as well as the health and safety of users.

Results: The smart handwashing station was deployed for 10 days in a school setting in Australia during the COVID-19 pandemic. The smart handwashing station's electrical components remained operational during field testing and underwent robust cleaning protocols each day. The handwashing station was used 1138 times during the field test and there was no COVID-19 transmission at the school during the testing.

Conclusions: This study demonstrates that a personalized feedback approach using technology can successfully be implemented at a school and can provide a platform to improve hand hygiene among school-aged children.

(*JMIR Public Health Surveill* 2020;6(4):e22305) doi:[10.2196/22305](https://doi.org/10.2196/22305)

KEYWORDS

COVID-19; hand hygiene; health promotion; public health; preventive medicine; digital health technology

Introduction

COVID-19, a contagious infectious disease caused by SARS-CoV-2, has emerged as a global health crisis and pandemic [1]. To stop the spread and transmission of this virus, behavioral interventions are needed across the population [1]. Hand hygiene is a critical public health control mechanism to prevent the spread of infectious pathogens as the most common way many communicable diseases are transmitted is via hands. Hand hygiene refers to hand cleansing, including washing hands with water and antimicrobial or nonantimicrobial soap, or applying an alcohol-based hand sanitizer to the hands. A meta-analysis suggests improved hand hygiene interventions

may reduce rates of gastrointestinal illness by 31% and respiratory illness by 21% [2]. Hand hygiene interventions have been shown to be cost-effective [3]; however, hand hygiene is often not sufficiently practiced, with studies reporting compliance rates between 40% and 60% in both the community and among health care workers [4-6].

Research has shown that COVID-19 can remain on environmental dry surfaces [7]; when a person touches the contaminated surface, they risk infection. Previous research into other coronaviruses (such as SARS-CoV) found that the virus can survive on environmental dry surfaces up to 6 days [8]. Hand hygiene is critically important because even if a person comes into contact with a contaminated surface with their hands,

they can avoid becoming infected by washing their hands before they touch their face. Face touching is common, with reports of medical students touching their faces 23 times per hour, 44% of which involved contact with mucous membranes (most commonly the mouth, followed by the nose and eyes) [9]. During the COVID-19 pandemic, germs may be spread more abundantly, with growing evidence suggesting it may be common to have no COVID-19 symptoms [10,11], resulting in these asymptomatic people unknowingly transmitting the virus to others. This is different from previous epidemics such as SARS, where most infected people were symptomatic. During COVID-19, strict social distancing guidelines have been enforced to restrict the spread of the disease in Australia and overseas. However, when restrictions are relaxed and normal routines resume, the flattened epidemic curve may rise again. After the initial outbreaks, COVID-19 may be expected to reoccur in waves, such as seasonally during winter [12]. Although vaccines are in development, we do not know their protective efficacy, nor the number of individuals willing to be vaccinated. Protective behavior such as good hand hygiene among our community will be a critical factor in the control of COVID-19.

Previous studies have shown that health education on hand hygiene alone is often ineffective at changing hygiene behaviors. Current hand hygiene education, such as visual signage, is generic and may not be personalized or unique to the individual. Increasingly, posters are made available at sinks to support the public in effective hand hygiene technique. Previously, hand hygiene posters showed multiple steps and therefore may have been difficult to follow. Recently, a simpler 3-step hand hygiene technique was found to improve technique and compliance compared to a 6-step technique [13]. However, posters that show the technique alone are the least effective for behavioral change, whereas multimodal technologies are much more effective [14]. An intervention using posters placed in university restrooms showed they had limited effect on hand hygiene [15]. Posters tend to act as reminders, and performance feedback is required to encourage optimal technique to ensure all areas of the hands are cleaned. The emotion of disgust has been shown to be a useful intervention strategy in promoting hand hygiene [16]; places considered dirty or with visible dirt proved to be strong hand-hygiene triggers [17]. Other determinants associated with successful hand-hygiene interventions include comfort, social norms, and habit [18].

There are limitations to the current methods of measuring hand hygiene compliance and performance. The World Health Organization (WHO) guidelines recommend that hand hygiene compliance should be assessed by direct observation by trained observers as the gold standard. Direct observation is currently recommended because it is the only approach that can detect all hand hygiene opportunities and actions to assess the number of times hand hygiene was required as well as the appropriate timing of handwashing [19]. Hand hygiene can also be assessed by self-report via interviews or questionnaires; however, self-assessment data are typically overestimated and do not correlate highly with compliance measured by direct observation [19]. Current technologies to measure compliance include electronic counting systems (ie, devices that count how often

the soap or sanitizer bottles were used), video monitoring, and automated monitoring systems [20]. The Internet of Things (IoT) is a concept where ordinary items are upgraded to include connectivity, allowing them to transmit information without requiring human interaction.

IoT-enabled smart devices were used in a hospital to measure how often hospital workers washed their hands; sensors monitored the flow of people and tracked disinfectant usage [21]. A limitation of compliance monitoring is that it does not measure hand hygiene performance, which can be analyzed using microbiological tests to assess bacterial counts. These include swab-based sampling for cultures, or finger imprints pressed onto an agar plate [22,23]. These require microbiological expertise and may involve dilutions and laboratory processing, which are time-consuming and costly [23].

During the COVID-19 pandemic, there has been a call for novel, digital behavioral interventions to facilitate adoption and maintenance of individual-level preventive behaviors [12]. In this study, we developed a smart handwashing station as a performance feedback approach to improving hand hygiene. Performance feedback interventions aim to increase awareness of behaviors and may serve as a motivator to continue to perform well or to improve performance [24]. A field test of the smart handwashing station was undertaken in a school setting. We examined key functionality aspects as well as implementation and regulatory considerations.

Methods

Smart Handwashing Station Development

In this study, we developed a smart handwashing station, incorporating a 365 nm UV light emitting diode (LED) light source, digital camera, and processing electronics within housing constructed from plastic and mounted on a stand. A commercially available pressure sensor mat (Radio Parts Pty Ltd) was connected via cable to a custom data acquisition system that reported pressure information in real time over a USB connection. Both the pressure sensor mat and the handwashing station were connected to a tablet (Acer Incorporated) via a USB cable. A software application written in Python triggered the camera to take a photo each time a person stood on the pressure sensor mat, and then every 5 seconds that they remained standing on the mat. All images were captured with timestamp information. Data was only stored locally on the tablet, and was periodically collected and sent to an off-site location. Although the device was supervised in this installation, it could easily be fixed to a specific location using a laptop-style antitheft lock.

Observational and Safety Testing

To check the smart handwashing station was connected and recording usage data correctly, observational testing was performed in Brisbane, Australia. Three volunteers (90 kg, 65 kg, and 30 kg) stood on the pressure sensor mat and used the smart handwashing station 10 times. The time-stamped data collected by the station was then compared with observational data.

The temperature of the smart handwashing station following 2 hours of continuous operation was recorded using an infrared

handheld thermometer (ThermaTwin TN410LCE Infrared Thermometer). The UV radiation emitted by the UV light source was measured using a UV intensity meter (Solar Light Co, Model PMA2100) fitted with a digital sensor (Solar Light Co, Model PMA2101). The detector head of the sensor was positioned with consideration of where a person's hands would be placed during use.

Smart Handwashing Station Deployment

The field study was conducted during the COVID-19 pandemic in April and May 2020, when handwashing was required every day. One smart handwashing station was deployed to a school located in Queensland, Australia. Children and adolescents aged 5-18 years attended the school, with over 1500 students enrolled. The smart handwashing station was placed near the school entry and outside handwashing facilities in a high-traffic area accessed by all students at the start of the day and during breaks. A moisturizer that contains a UV-fluorescent compound (BREVIS Corporation) was dispensed using a touchless automatic system (D cor House).

Feedback was obtained from end users, including teachers and teaching assistants, to design and refine the device. Questions regarding logistics were asked (eg, battery requirements, transport, and if the image quality was sufficient). In addition, email and phone contact details of the researchers were displayed and provided to the teachers for complaints, technical issues, or further information during the deployment. The deployment of the smart handwashing station was to assess device functionality and not human subjects research; therefore, we obtained an institutional ethics review board exemption from the Human Research Ethics Committee of the Queensland University of Technology.

Statistical Analysis

Observational testing of the handwashing station dichotomized usage variables to categorical data: handwashing usage data was coded "yes" if timestamped data was recorded to the tablet and coded "no" if the handwashing station was used but no data

was recorded to the tablet. The Cohen κ score was calculated to determine if there was agreement between categorical variables for handwashing usage. Values of 0.4-0.6 were considered moderate agreement, values of 0.6-0.8 were considered substantial agreement, and values of 0.8-1.0 were considered almost perfect agreement. GraphPad Prism (Version 8, GraphPad Software Inc) and SPSS (Version 25.0, IBM Corp) were used for analyses.

Results

Smart Handwashing Station Operational Function and Safety Testing

A prototype smart handwashing station was developed, which uses a UV light source and digital camera to provide personalized feedback on hand hygiene (Figure 1). First, the user applies a moisturizer that contains a UV-fluorescent compound. Second, the user washes their hands and checks their hands at the station (Multimedia Appendix 1). Any areas highlighted have not been washed enough to remove the moisturizer, indicating missed areas that require further washing. This visualization tool provides personalized feedback about where improvements can be made for each user (Figure 2).

The smart handwashing station integrated IoT approaches to track usage and collect images of users' hands. Observational testing of the smart handwashing station demonstrated there was perfect agreement with observed handwashing and station-recorded usage ($\kappa=1.0$, 95% CI 1.00-1.00; Table 1).

The prototype unit emits only UV-A radiation. Over 7 hours of continuous exposure would be needed to equal the level of UV-A received in 15 minutes from the summer sun in Brisbane, Australia. During testing, no skin irritation was reported or observed after participants used the station or the fluorescent moisturizer. The temperature of the smart handwashing station following 2 hours of continuous operation was 28.1 °C on the top of the housing and 25.3 °C on the underside, where the light source is emitted.

Figure 1. Smart handwashing station with electrical components housed within the top box.

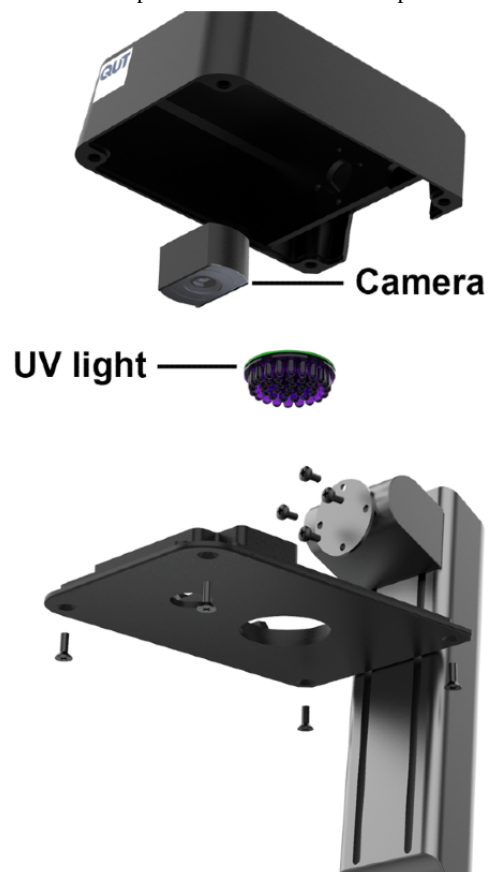


Figure 2. The smart handwashing station was mounted on a stand with a tablet connected to display images.



Table 1. Agreement between observed handwashing usage and station-recorded measurements.

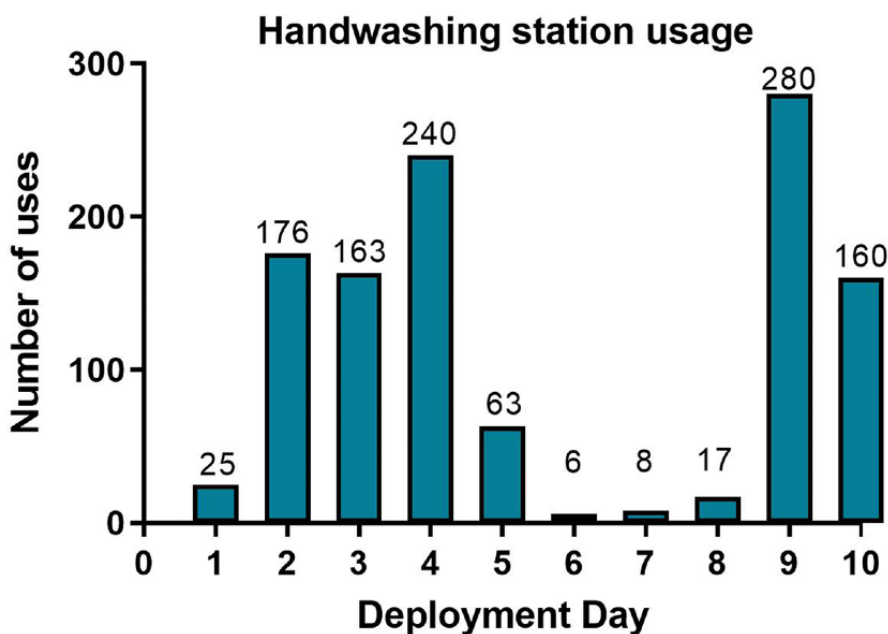
Weight of person	Station-reported usage (N=10)	
	Yes, n (%)	No, n (%)
90 kg	10 (100)	0 (0)
65 kg	10 (100)	0 (0)
30 kg	10 (100)	0 (0)

Field Testing of Smart Handwashing Station

The smart handwashing station recorded data each day during deployment at the school (Figure 3). No complaints, adverse events, or concerns were logged from users or teachers during the 10 days the smart handwashing station was deployed. The handwashing station was stored on a trolley for ease of transport across the school campus and placed outside handwashing facilities in high-traffic areas (Multimedia Appendix 2). The handwashing station was designed so the users did not have to touch or rest their hands on any surface; rather, they could hover

their hands between the desk and top of the station. A COVID-19 case was reported at the school several weeks prior to the deployment of the station. During deployment, no transmission of COVID-19 was recorded at the school. The laptop provided sufficient power via the USB connection during field testing. The smart handwashing station was stored in an air-conditioned laboratory room when not in use and the laptop was recharged. The UV light source and digital camera consumed an average of 5 watts of power. As a result, even the relatively small tablet battery was sufficient for over 4 hours of recording before requiring recharging.

Figure 3. Field testing results of the smart handwashing station. The graph depicts the number of times the smart handwashing station was used each day.



Discussion

Our data demonstrated that the smart handwashing station can provide a visual tool to schoolchildren by highlighting areas on their hands missed during handwashing. The smart handwashing station accurately recorded time-stamped usage data in a school setting in Australia. During the 10-day field test, the smart handwashing station electrical components remained operational and data was received each day, resulting in 100% connectivity. No safety concerns or adverse events occurred when the smart sunscreen station and fluorescent lotion were used by children and adolescents aged 5-18 years. Based on these results, we suggest that the smart handwashing station may become a valuable tool to provide personalized performance feedback on hand hygiene and could help to optimize handwashing techniques in children and adolescents.

Recent advances in technology and wearable sensors have made it possible to measure handwashing performance via automated systems, rather than relying on direct observation with trained observers. Galluzzi et al [25] assessed motion-sensor wristbands that collected data on compliance with the WHO handwashing steps in a clinical setting and found hand hygiene motions could be classified with up to 93% accuracy. However, participants were required to wear the wristbands during handwashing, while the WHO handwashing guidelines recommend removing rings, wristwatches, and bracelets before handwashing; therefore, these wristbands could potentially house infectious pathogens, impeding hand hygiene. Other research assessing the use of hand gestures during handwashing have used armbands placed on forearms and reported recognition rates of 98% and 97%, respectively [26,27]. Armbands increase the mobility of monitoring devices in comparison to stationary devices such as

fixed monitoring cameras next to sinks, which have additional privacy concerns due to the collection of identifiable images of people. These wearable sensor trials were also limited by the ability to assess for handedness and its impact on measurements. Most wearable sensor technologies have been developed to measure hand hygiene compliance in health care settings and there may be significant barriers to overcome when implementing this technology in community settings.

This study evaluated the use of a handwashing station in a school environment, which is an ideal setting to introduce health information to young children and teenagers. Children are prone to acquiring acute respiratory illness due to a tendency to put items and their hands in their mouths and noses regularly; such illnesses are transmitted to parents in more than 30% of cases [28]. Studies suggest that modelling handwashing for children, either in-person or by video, when combined with other strategies, can increase correct handwashing [29]. Blacklight technology and UV-sensitive simulated germ lotions have previously been used in school and health care settings and have demonstrated improved handwashing practices using water and soap [30-35] and alcohol-based sanitizers [36], with one study of preschool-aged children reporting a 44% increase in handwashing quality scores [32]. In contrast, Oncu et al [37] reported that the use of blacklight technology and a fluorescent lotion did not increase handwashing quality in primary school students. These previous studies were all conducted prior to the COVID-19 pandemic and future studies exploring behavior change in response to personalized visual feedback may have greater improvements due to the increased awareness of the importance of hand hygiene among the general population.

The smart handwashing station designed during this study was purpose-built to overcome barriers health interventions faced during the pandemic. The smart handwashing station does not require any human interaction during operation and removed the need for a staffing resource during deployment and data collection. Social distancing restrictions were also considered when developing the station, with users able to move from the automatic lotion dispenser to sink areas for washing and then to the station to view feedback in a well-ventilated outdoor space. As it is possible for a person to contract COVID-19 by touching a surface or object that has the virus on it and then touching their own mouth [7], the smart handwashing station

was designed as a touch-free platform, with the user's hands hovering between the desk and top of the station. The station was developed to capture data to provide insights into hand hygiene without being resource intensive; it does not require any infrastructure, such as installed sensors in washrooms. The mobility of the station is also a key design feature; as it is a small unit, it can easily be shipped and deployed in many configurations. The station incorporates IoT capabilities, with time-stamped data collected and images captured. Future work could explore the potential to undertake image analysis on the collected images and generate handwashing quality scores. Technology has the capacity to accelerate and assist public health infectious disease controls and IoT devices may form an essential part of future public health infrastructure and preparedness.

Key technical considerations for a successful deployment included appropriate design for use by school students, with a robust structure, a software system that operates with current organizational platforms, and careful consideration of the configuration to ensure privacy and minimize security risks. Ensuring secure and reliable operation is an important consideration in technology-based deployments, particularly in community areas. The health information gathered by devices during a pandemic can provide potentially critical information to assist public health agencies; however, the information generated needs to be processed in a way that will assist and not overwhelm time-poor health professionals. The flow of information from deployed smart handwashing stations to an online dashboard is shown in Figure 4, illustrating the potential to collect and integrate data to reduce the impact of COVID-19. The use of infographics with overlaid geospatial information can provide insights into potential at-risk populations with low levels of hand hygiene in the community. Delivering targeted prevention programs is essential during a pandemic. With subsequent waves of infections in many countries linked to asymptomatic children and young adults [38,39], interventions that improve hand hygiene in this population are critical. School and college campuses reach high numbers of this target population and this study has shown a smart handwashing station can be deployed in this environment. The economic costs of outbreak-associated lockdowns of schools, travel, and businesses to control the spread of disease are substantial, further highlighting the importance of prevention measures.

Figure 4. The flow of data from deployed smart handwashing stations to an online dashboard, overlaid with geospatial information. The smart handwashing station could collect data on hand hygiene by analyzing images and determining areas not washed sufficiently (left panel). This information could be used to generate an online dashboard (center panel) indicating the number of times the station was used, as well as the quality of the handwashing, with orange illustrating the frequency of poor handwashing and green representing good handwashing. This information could be overlaid with geospatial data from the location of the handwashing station to indicate areas with poor hand hygiene that have a potentially high risk of transmission (right panel). A graded series of colours could be used to represent risk on a map. The use of pictograms to illustrate the handwashing station data could benefit the translation of information to public health agencies and assist in the delivery of targeted public health programs.



The development of new health care devices creates opportunities for skills and knowledge creation through the research process [40]. The smart handwashing station was developed using a stepwise approach, which included first identifying COVID-19 as the target disease and the unmet need of reducing disease transmission by improving hand hygiene. The mechanism by which therapeutic benefits could be derived was then explored and early testing was performed to demonstrate the basic principles of the device. Initial prototyping involved identifying potential challenges in manufacturing, including supply chain delays due to the pandemic. By repurposing computer monitor stands to form the device stand, we were able to overcome potential manufacturing delays and begin preclinical testing. Stakeholder consulting was undertaken and involved discussion of practical elements, such as ease of use and integration into existing practice. This led to determining the school setting as a suitable community site for field testing the prototype device. Schools and colleges have large numbers of children and young adults and the existing education to increase handwashing was in the form of handwashing posters. Comparing the effectiveness of the smart handwashing station's personalized feedback with printed posters will form part of future research. Before undertaking clinical trials, manufacturing elements including material quality, tooling setup, transport, and shelf-life need to be considered to produce clinical trial prototypes as close to the final device form as possible.

This device would be a low-risk class-1 medical device requiring registration with the Therapeutic Goods Administration (TGA) as a medical device in order to be lawfully sold in Australia. The definition of what constitutes a medical device has recently been updated in Australia by the TGA, with amendments aligning more closely with the equivalent definitions in the European Union's Regulation (EU) 2017/745. The Federal Drug Administration (FDA) ensures that the claims made by a medical product accurately reflect its risks and benefits in the US market. The regulatory framework determining the medical device approval processes are based on relative risk. Medical devices

include a diverse range of devices, from toothbrushes to software. Accelerated approval may be allowed by many regulators if a device can provide evidence that it is substantially similar to an existing device in terms of materials and safety, or if the risk class is sufficiently low as to need relatively little safety data.

While observation is accepted as the gold standard when evaluating handwashing effectiveness, it can be costly and time-consuming, as well as difficult to implement during a pandemic when social distancing and shelter-in-place restrictions are imposed by many governments [41]. Microbiological analysis is another method that can be used to evaluate handwashing effectiveness; however, it requires laboratory processing, which may be impacted during a pandemic as resources are shifted toward screening programs. Microbial flora analysis is a time-consuming process that provides no initial feedback to the user. In addition, the analysis can be impacted by interpersonal variations of permanent skin microflora [23]. The handwashing station in this study included a UV-fluorescent lotion and we assumed that fluorescent-covered parts of the hands would indicate pathogens that remained after washing; however, microbiological validity was not performed in this study.

A limitation of this study is that we did not analyze the usage data or the captured image data to investigate behavior change. In addition, the duration of field testing was only 10 days. Detailed qualitative data was not collected from users. Future research could expand on the enablers and barriers to hand hygiene in schools. In this proof-of-concept study, we did not monitor students' hand hygiene compliance or handwashing quality. The placement of the station needs to be within close proximity to handwashing facilities and the station was not optimized for hand sanitizer. The Centers for Disease Control and Prevention in the United States recommends using alcohol-based sanitizers only when soap and water are inaccessible. Handwashing using soap and water is more

effective for removing most types of microorganisms than using hand sanitizers [42]. Wearing gloves does not replace hand hygiene in the community, as gloves do not provide complete protection against hand contamination and it is not practical for schoolchildren or those in the community to routinely wear gloves.

Future research should explore image analysis approaches to objectively measure hand hygiene levels in the community. Testing satisfaction with the smart handwashing station could be expanded to other settings, including public spaces such as airports, shopping centers, recreational venues, and workplaces. The smart handwashing station shows significant promise for generating relevant data for public health authorities on hand hygiene practices in the community. The smart handwashing station data could be used to inform targeted training as part of

health programs in areas with poor handwashing, as well as assist inventory management systems to ensure appropriate levels of soap are always available.

Handwashing is an essential process to reduce the spread of infectious pathogens. This study developed a handwashing station, which used a simple and cheap method that was easily understood by school-aged children. To assist schools to protect their students from outbreaks, the smart handwashing station could help build awareness of the importance of hand hygiene and provide personalized feedback. The usage data generated by this device could also benefit health programs by informing public health authorities of areas with low handwashing where targeted training may increase hand hygiene. This study provides evidence for the technical feasibility of smart handwashing stations in a school setting.

Acknowledgments

The authors would like to thank Meridan State College for their support in deploying the handwashing device and Anthony Weate for producing the video of the operational function of the handwashing station. The sponsors of the study (Queensland Government Advance Queensland fund) had no role in the study design; collection, analysis, and interpretation of data; in the writing of this manuscript; or in the decision to submit the paper for publication. The corresponding author had full access to all data in the study and final responsibility for the decision to submit this study for publication.

Conflicts of Interest

Authors HF, CH, and EH state no conflicts of interest. Authors JH and AW are employees of Designworks group.

Multimedia Appendix 1

Operational function of the smart handwashing station providing personalized feedback on hand hygiene.

[MP4 File (MP4 Video), 127865 KB - [publichealth_v6i4e22305_app1.mp4](#)]

Multimedia Appendix 2

The handwashing station deployed on a trolley outside handwashing facilities in a high-traffic area.

[PNG File , 607 KB - [publichealth_v6i4e22305_app2.png](#)]

References

1. Cohen MS, Corey L. Combination prevention for COVID-19. *Science* 2020 May 08;368(6491):551. [doi: [10.1126/science.abc5798](#)] [Medline: [32381692](#)]
2. Aiello AE, Coulborn RM, Perez V, Larson EL. Effect of hand hygiene on infectious disease risk in the community setting: a meta-analysis. *Am J Public Health* 2008 Aug;98(8):1372-1381. [doi: [10.2105/AJPH.2007.124610](#)] [Medline: [18556606](#)]
3. Graves N, Page K, Martin E, Brain D, Hall L, Campbell M, et al. Cost-Effectiveness of a National Initiative to Improve Hand Hygiene Compliance Using the Outcome of Healthcare Associated Staphylococcus aureus Bacteraemia. *PLoS One* 2016;11(2):e0148190 [FREE Full text] [doi: [10.1371/journal.pone.0148190](#)] [Medline: [26859688](#)]
4. Pittet D, Simon A, Hugonnet S, Pessoa-Silva CL, Sauvan V, Perneger TV. Hand hygiene among physicians: performance, beliefs, and perceptions. *Ann Intern Med* 2004 Jul 06;141(1):1-8. [doi: [10.7326/0003-4819-141-1-200407060-00008](#)] [Medline: [15238364](#)]
5. Guinan ME, McGuckin-Guinan M, Severeid A. Who washes hands after using the bathroom? *Am J Infect Control* 1997 Oct;25(5):424-425. [doi: [10.1016/s0196-6553\(97\)90092-4](#)] [Medline: [9343628](#)]
6. Erasmus V, Daha TJ, Brug H, Richardus JH, Behrendt MD, Vos MC, et al. Systematic review of studies on compliance with hand hygiene guidelines in hospital care. *Infect Control Hosp Epidemiol* 2010 Mar;31(3):283-294. [doi: [10.1086/650451](#)] [Medline: [20088678](#)]
7. Ong SWX, Tan YK, Chia PY, Lee TH, Ng OT, Wong MSY, et al. Air, Surface Environmental, and Personal Protective Equipment Contamination by Severe Acute Respiratory Syndrome Coronavirus 2 (SARS-CoV-2) From a Symptomatic Patient. *JAMA* 2020 Apr 28;323(16):1610-1612 [FREE Full text] [doi: [10.1001/jama.2020.3227](#)] [Medline: [32129805](#)]

8. Otter JA, Donskey C, Yezli S, Douthwaite S, Goldenberg SD, Weber DJ. Transmission of SARS and MERS coronaviruses and influenza virus in healthcare settings: the possible role of dry surface contamination. *J Hosp Infect* 2016 Mar;92(3):235-250 [FREE Full text] [doi: [10.1016/j.jhin.2015.08.027](https://doi.org/10.1016/j.jhin.2015.08.027)] [Medline: [26597631](https://pubmed.ncbi.nlm.nih.gov/26597631/)]
9. Kwok YLA, Gralton J, McLaws M. Face touching: a frequent habit that has implications for hand hygiene. *Am J Infect Control* 2015 Feb;43(2):112-114 [FREE Full text] [doi: [10.1016/j.ajic.2014.10.015](https://doi.org/10.1016/j.ajic.2014.10.015)] [Medline: [25637115](https://pubmed.ncbi.nlm.nih.gov/25637115/)]
10. Day M. Covid-19: four fifths of cases are asymptomatic, China figures indicate. *BMJ* 2020 Apr 02;369:m1375. [doi: [10.1136/bmj.m1375](https://doi.org/10.1136/bmj.m1375)] [Medline: [32241884](https://pubmed.ncbi.nlm.nih.gov/32241884/)]
11. Yang R, Gui X, Xiong Y. Comparison of Clinical Characteristics of Patients with Asymptomatic vs Symptomatic Coronavirus Disease 2019 in Wuhan, China. *JAMA Netw Open* 2020 May 01;3(5):e2010182 [FREE Full text] [doi: [10.1001/jamanetworkopen.2020.10182](https://doi.org/10.1001/jamanetworkopen.2020.10182)] [Medline: [32459353](https://pubmed.ncbi.nlm.nih.gov/32459353/)]
12. Allegrante JP, Auld ME, Natarajan S. Preventing COVID-19 and Its Sequela: "There Is No Magic Bullet... It's Just Behaviors". *Am J Prev Med* 2020 Aug;59(2):288-292 [FREE Full text] [doi: [10.1016/j.amepre.2020.05.004](https://doi.org/10.1016/j.amepre.2020.05.004)] [Medline: [32591282](https://pubmed.ncbi.nlm.nih.gov/32591282/)]
13. Tschudin-Sutter S, Sepulcri D, Dangel M, Ulrich A, Frei R, Widmer AF. Simplifying the World Health Organization Protocol: 3 Steps Versus 6 Steps for Performance of Hand Hygiene in a Cluster-randomized Trial. *Clin Infect Dis* 2019 Aug 01;69(4):614-620. [doi: [10.1093/cid/ciy948](https://doi.org/10.1093/cid/ciy948)] [Medline: [30395180](https://pubmed.ncbi.nlm.nih.gov/30395180/)]
14. Jenner EA, Jones F, Fletcher BC, Miller L, Scott GM. Hand hygiene posters: selling the message. *J Hosp Infect* 2005 Feb;59(2):77-82. [doi: [10.1016/j.jhin.2004.07.002](https://doi.org/10.1016/j.jhin.2004.07.002)] [Medline: [15702513](https://pubmed.ncbi.nlm.nih.gov/15702513/)]
15. Lawson A, Vaganay-Miller M. The Effectiveness of a Poster Intervention on Hand Hygiene Practice and Compliance When Using Public Restrooms in a University Setting. *Int J Environ Res Public Health* 2019 Dec 11;16(24) [FREE Full text] [doi: [10.3390/ijerph16245036](https://doi.org/10.3390/ijerph16245036)] [Medline: [31835651](https://pubmed.ncbi.nlm.nih.gov/31835651/)]
16. Porzig-Drummond R, Stevenson R, Case T, Oaten M. Can the emotion of disgust be harnessed to promote hand hygiene? Experimental and field-based tests. *Soc Sci Med* 2009 Mar;68(6):1006-1012. [doi: [10.1016/j.socscimed.2009.01.013](https://doi.org/10.1016/j.socscimed.2009.01.013)] [Medline: [19181428](https://pubmed.ncbi.nlm.nih.gov/19181428/)]
17. Whitby M, McLaws M, Ross MW. Why healthcare workers don't wash their hands: a behavioral explanation. *Infect Control Hosp Epidemiol* 2006 May;27(5):484-492. [doi: [10.1086/503335](https://doi.org/10.1086/503335)] [Medline: [16671030](https://pubmed.ncbi.nlm.nih.gov/16671030/)]
18. Judah G, Aunger R, Schmidt W, Michie S, Granger S, Curtis V. Experimental pretesting of hand-washing interventions in a natural setting. *Am J Public Health* 2009 Oct;99 Suppl 2:S405-S411. [doi: [10.2105/AJPH.2009.164160](https://doi.org/10.2105/AJPH.2009.164160)] [Medline: [19797755](https://pubmed.ncbi.nlm.nih.gov/19797755/)]
19. World Health Organization. WHO Guidelines on Hand Hygiene in Health Care. 2009. URL: www.who.int/gpsc/5may/tools/9789241597906/en/ [accessed 2020-10-13]
20. Ward MA, Schweizer ML, Polgreen PM, Gupta K, Reisinger HS, Perencevich EN. Automated and electronically assisted hand hygiene monitoring systems: a systematic review. *Am J Infect Control* 2014 May;42(5):472-478. [doi: [10.1016/j.ajic.2014.01.002](https://doi.org/10.1016/j.ajic.2014.01.002)] [Medline: [24773785](https://pubmed.ncbi.nlm.nih.gov/24773785/)]
21. Yamashita Y, Iwasaki H, Muroi Y, Hida M, Shigemi H. Development of In-Hospital Infection Management Using IoT. *Stud Health Technol Inform* 2019 Aug 21;264:1817-1818. [doi: [10.3233/SHTI190663](https://doi.org/10.3233/SHTI190663)] [Medline: [31438359](https://pubmed.ncbi.nlm.nih.gov/31438359/)]
22. Hansen TB, Knöchel S. Image analysis method for evaluation of specific and non-specific hand contamination. *J Appl Microbiol* 2003;94(3):483-494. [doi: [10.1046/j.1365-2672.2003.01855.x](https://doi.org/10.1046/j.1365-2672.2003.01855.x)] [Medline: [12588557](https://pubmed.ncbi.nlm.nih.gov/12588557/)]
23. Zapka C, Leff J, Henley J, Tittl J, De Nardo E, Butler M, et al. Comparison of Standard Culture-Based Method to Culture-Independent Method for Evaluation of Hygiene Effects on the Hand Microbiome. *mBio* 2017 Mar 28;8(2). [doi: [10.1128/mBio.00093-17](https://doi.org/10.1128/mBio.00093-17)] [Medline: [28351915](https://pubmed.ncbi.nlm.nih.gov/28351915/)]
24. Gould DJ, Moralejo D, Drey N, Chudleigh JH, Taljaard M. Interventions to improve hand hygiene compliance in patient care. *Cochrane Database Syst Rev* 2017 Sep 01;9:CD005186 [FREE Full text] [doi: [10.1002/14651858.CD005186.pub4](https://doi.org/10.1002/14651858.CD005186.pub4)] [Medline: [28862335](https://pubmed.ncbi.nlm.nih.gov/28862335/)]
25. Galluzzi V, Herman T, Polgreen P. Hand hygiene duration and technique recognition using wrist-worn sensors. In: *IPSN '15: Proceedings of the 14th International Conference on Information Processing in Sensor Networks*. 2015 Presented at: 14th International Conference on Information Processing in Sensor Networks; April 2015; Seattle, Washington, USA p. 106-117. [doi: [10.1145/2737095.2737106](https://doi.org/10.1145/2737095.2737106)]
26. Kutafina E, Laukamp D, Bettermann R, Schroeder U, Jonas SM. Wearable Sensors for eLearning of Manual Tasks: Using Forearm EMG in Hand Hygiene Training. *Sensors (Basel)* 2016 Aug 03;16(8) [FREE Full text] [doi: [10.3390/s16081221](https://doi.org/10.3390/s16081221)] [Medline: [27527167](https://pubmed.ncbi.nlm.nih.gov/27527167/)]
27. Wang C, Sarsenbayeva Z, Chen X, Dingler T, Goncalves J, Kostakos V. Accurate Measurement of Handwash Quality Using Sensor Armbands: Instrument Validation Study. *JMIR mHealth uHealth* 2020 Mar 26;8(3):e17001 [FREE Full text] [doi: [10.2196/17001](https://doi.org/10.2196/17001)] [Medline: [32213469](https://pubmed.ncbi.nlm.nih.gov/32213469/)]
28. Sacri AS, De Serres G, Quach C, Boulianne N, Valiquette L, Skowronski DM. Transmission of acute gastroenteritis and respiratory illness from children to parents. *Pediatr Infect Dis J* 2014 Jun;33(6):583-588. [doi: [10.1097/INF.0000000000000220](https://doi.org/10.1097/INF.0000000000000220)] [Medline: [24476955](https://pubmed.ncbi.nlm.nih.gov/24476955/)]
29. Jess RL, Dozier CL. Increasing handwashing in young children: A brief review. *J Appl Behav Anal* 2020 Jul;53(3):1219-1224. [doi: [10.1002/jaba.732](https://doi.org/10.1002/jaba.732)] [Medline: [32639051](https://pubmed.ncbi.nlm.nih.gov/32639051/)]

30. Snow M, White GL, Kim HS. Inexpensive and time-efficient hand hygiene interventions increase elementary school children's hand hygiene rates. *J Sch Health* 2008 Apr;78(4):230-233. [doi: [10.1111/j.1746-1561.2008.00291.x](https://doi.org/10.1111/j.1746-1561.2008.00291.x)] [Medline: [18336683](https://pubmed.ncbi.nlm.nih.gov/18336683/)]
31. Fishbein AB, Tellez I, Lin H, Sullivan C, Groll ME. Glow gel hand washing in the waiting room: a novel approach to improving hand hygiene education. *Infect Control Hosp Epidemiol* 2011 Jul;32(7):661-666. [doi: [10.1086/660359](https://doi.org/10.1086/660359)] [Medline: [21666396](https://pubmed.ncbi.nlm.nih.gov/21666396/)]
32. Dingman D, Wu J, Murphy HM. School-based, blacklight handwashing program can improve handwashing quality and knowledge among pre-school aged children. *Eval Program Plann* 2020 Feb;78:101731. [doi: [10.1016/j.evalprogplan.2019.101731](https://doi.org/10.1016/j.evalprogplan.2019.101731)] [Medline: [31756601](https://pubmed.ncbi.nlm.nih.gov/31756601/)]
33. Au W, Suen L, Kwok Y. Handwashing programme in kindergarten: a pilot study. *Health Education* 2010 Jan 05;110(1):5-16. [doi: [10.1108/09654281011008717](https://doi.org/10.1108/09654281011008717)]
34. Szilágyi L, Haidegger T, Lehotsky A, Nagy M, Csonka E, Sun X, et al. A large-scale assessment of hand hygiene quality and the effectiveness of the. *BMC Infect Dis* 2013 May 30;13:249 [FREE Full text] [doi: [10.1186/1471-2334-13-249](https://doi.org/10.1186/1471-2334-13-249)] [Medline: [23718728](https://pubmed.ncbi.nlm.nih.gov/23718728/)]
35. Jess RL, Dozier CL, Foley EA. Effects of a handwashing intervention package on handwashing in preschool children. *Behavioral Interventions* 2019 Jul 19;34(4):475-486. [doi: [10.1002/bin.1684](https://doi.org/10.1002/bin.1684)]
36. Macdonald DJM, McKillop ECA, Trotter S, Gray A. Improving hand-washing performance - a crossover study of hand-washing in the orthopaedic department. *Ann R Coll Surg Engl* 2006 May;88(3):289-291 [FREE Full text] [doi: [10.1308/003588406X98577](https://doi.org/10.1308/003588406X98577)] [Medline: [16720001](https://pubmed.ncbi.nlm.nih.gov/16720001/)]
37. Öncü E, Vayisoğlu SK, Lafci D, Yurtsever D, Bulut ER, Peker E. Comparison of Interactive Education Versus Fluorescent Concretization on Hand Hygiene Compliance Among Primary School Students: A Randomized Controlled Trial. *J Sch Nurs* 2019 Oct;35(5):337-347. [doi: [10.1177/1059840518785447](https://doi.org/10.1177/1059840518785447)] [Medline: [29973117](https://pubmed.ncbi.nlm.nih.gov/29973117/)]
38. Panovska-Griffiths J, Kerr CC, Stuart RM, Mistry D, Klein DJ, Viner RM, et al. Determining the optimal strategy for reopening schools, the impact of test and trace interventions, and the risk of occurrence of a second COVID-19 epidemic wave in the UK: a modelling study. *Lancet Child Adolesc Health* 2020 Aug 03 [FREE Full text] [doi: [10.1016/S2352-4642\(20\)30250-9](https://doi.org/10.1016/S2352-4642(20)30250-9)] [Medline: [32758453](https://pubmed.ncbi.nlm.nih.gov/32758453/)]
39. DeBiasi RL, Delaney M. Symptomatic and Asymptomatic Viral Shedding in Pediatric Patients Infected With Severe Acute Respiratory Syndrome Coronavirus 2 (SARS-CoV-2): Under the Surface. *JAMA Pediatr* 2020 Aug 28. [doi: [10.1001/jamapediatrics.2020.3996](https://doi.org/10.1001/jamapediatrics.2020.3996)] [Medline: [32857158](https://pubmed.ncbi.nlm.nih.gov/32857158/)]
40. Mehta SS. *Commercializing Successful Biomedical Technologies*. Cambridge, UK: Cambridge University Press; 2008.
41. Haas JP, Larson EL. Measurement of compliance with hand hygiene. *J Hosp Infect* 2007 May;66(1):6-14. [doi: [10.1016/j.jhin.2006.11.013](https://doi.org/10.1016/j.jhin.2006.11.013)] [Medline: [17276546](https://pubmed.ncbi.nlm.nih.gov/17276546/)]
42. Charbonneau DL, Ponte JM, Kochanowski BA. A method of assessing the efficacy of hand sanitizers: use of real soil encountered in the food service industry. *J Food Prot* 2000 Apr;63(4):495-501. [doi: [10.4315/0362-028x-63.4.495](https://doi.org/10.4315/0362-028x-63.4.495)] [Medline: [10772215](https://pubmed.ncbi.nlm.nih.gov/10772215/)]

Abbreviations

IoT: Internet of Things

TGA: Therapeutic Goods Administration

WHO: World Health Organization

Edited by G Eysenbach, R Kukafka; submitted 29.07.20; peer-reviewed by E Kutafina, A Benis; comments to author 22.08.20; revised version received 03.09.20; accepted 22.09.20; published 19.10.20.

Please cite as:

Herbert J, Horsham C, Ford H, Wall A, Hacker E

Deployment of a Smart Handwashing Station in a School Setting During the COVID-19 Pandemic: Field Study

JMIR Public Health Surveill 2020;6(4):e22305

URL: <http://publichealth.jmir.org/2020/4/e22305/>

doi: [10.2196/22305](https://doi.org/10.2196/22305)

PMID: [33006559](https://pubmed.ncbi.nlm.nih.gov/33006559/)

©Jeremy Herbert, Caitlin Horsham, Helen Ford, Alexander Wall, Elke Hacker. Originally published in *JMIR Public Health and Surveillance* (<http://publichealth.jmir.org>), 19.10.2020. This is an open-access article distributed under the terms of the Creative Commons Attribution License (<https://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in *JMIR Public Health and Surveillance*, is properly

cited. The complete bibliographic information, a link to the original publication on <http://publichealth.jmir.org>, as well as this copyright and license information must be included.

Original Paper

Diagnostic Accuracy of Chest Computed Tomography Scans for Suspected Patients With COVID-19: Receiver Operating Characteristic Curve Analysis

Lianpin Wu¹, MD; Qike Jin¹, MD; Jie Chen², MD, PhD; Jiawei He¹, MD; David M Brett-Major³, MD; Jianghu James Dong⁴, PhD

¹Department of Cardiology, the Second Affiliated Hospital & Yuying Children's Hospital of Wenzhou Medical University, Wenzhou, China

²College of Optometry, Wenzhou Medical University, Wenzhou, China

³Department of Epidemiology, University of Nebraska Medical Center, Omaha, NE, United States

⁴Department of Biostatistics and Department of Medicine, University of Nebraska Medical Center, Omaha, NE, United States

Corresponding Author:

Jianghu James Dong, PhD

Department of Biostatistics and Department of Medicine

University of Nebraska Medical Center

984375 Nebraska Medical Center

Omaha, NE, 68198-4375

United States

Phone: 1 402 559 1976

Email: jianghu.dong@unmc.edu

Related Article:

This is a corrected version. See correction statement: <https://publichealth.jmir.org/2020/4/e25829/>

Abstract

Background: Computed tomography (CT) scans are increasingly available in clinical care globally. They enable a rapid and detailed assessment of tissue and organ involvement in disease processes that are relevant to diagnosis and management, particularly in the context of the COVID-19 pandemic.

Objective: The aim of this paper is to identify differences in the CT scan findings of patients who were COVID-19 positive (confirmed via nucleic acid testing) to patients who were confirmed COVID-19 negative.

Methods: A retrospective cohort study was proposed to compare patient clinical characteristics and CT scan findings in suspected COVID-19 cases. A multivariable logistic model with LASSO (least absolute shrinkage and selection operator) selection for variables was used to identify the good predictors from all available predictors. The area under the curve (AUC) with 95% CI was calculated for each of the selected predictors and the combined selected key predictors based on receiver operating characteristic curve analysis.

Results: A total of 94 (56%) patients were confirmed positive for COVID-19 from the suspected 167 patients. We found that elderly people were more likely to be infected with COVID-19. Among the 94 confirmed positive patients, 2 (2%) patients were admitted to an intensive care unit. No patients died during the study period. We found that the presence, distribution, and location of CT lesions were associated with the presence of COVID-19. White blood cell count, cough, and a travel history to Wuhan were also the top predictors for COVID-19. The overall AUC of these selected predictors is 0.97 (95% CI 0.93-1.00).

Conclusions: Taken together with nucleic acid testing, we found that CT scans can allow for the rapid diagnosis of COVID-19. This study suggests that chest CT scans should be more broadly adopted along with nucleic acid testing in the initial assessment of suspected COVID-19 cases, especially for patients with nonspecific symptoms.

(*JMIR Public Health Surveill* 2020;6(4):e19424) doi:[10.2196/19424](https://doi.org/10.2196/19424)

KEYWORDS

COVID-19; chest CT scans; nucleic acid testing; retrospective cohort study; AUC; ROC

Introduction

In December 2019, multiple cases of pneumonia were detected in Wuhan, Hubei Province, China [1]. These patients had nonspecific symptoms including variable fever, cough, breathing difficulties, muscle aches, and fatigue. Ultimately, this would prove to be the seed of a pandemic, named by the World Health Organization as COVID-19 [2], caused by the seventh member of the human-infecting coronavirus family, SARS-CoV-2. Other notable members in the same family are the severe acute respiratory syndrome (SARS) coronavirus and the Middle East respiratory syndrome (MERS) coronavirus, which have caused significant public health hazards. COVID-19 can be transmitted from person to person through droplets, contact, or through the fecal-oral route, with a high degree of communicability [3]. Since January 2020, COVID-19 has spread to most parts of China as well as the world, posing an extensive threat to global public health by seriously affecting the quality of life of millions of people. Large numbers of people across China were returning to their hometown from Wuhan for the Chinese Lunar New Year [4], making our region a COVID-19 epicenter. This retrospective study collected consecutively hospitalized patients with a suspected case of COVID-19 dating to the end of January 2020 at a single tertiary care referral hospital in Zhejiang Province. As of this writing, the epidemic in this region was well under control with few new cases and deaths from COVID-19.

In the context of this emergency and the need to move past nonspecific symptoms to approaches that allow for early diagnosis and management, we wanted to investigate potential differences in the chest CT scans of patients who were COVID-19 positive to those who were COVID-19 negative (confirmed via nucleic acid test). To demonstrate factors relevant to clinical outcomes, we wanted to compare patients with a confirmed positive case of COVID-19 to those with a negative result based on characteristics, interventions, and outcomes. This motivated us to propose a retrospective cohort approach for COVID-19 research. Several case-control studies have been carried out to investigate the clinical outcome of COVID-19. For example, several clinical characteristics have been identified in pregnant women and their neonates with COVID-19 [5]. Furthermore, COVID-19 is known to cause smell and taste disorders in those who are infected with the disease, particularly at a higher rate than patients with influenza [6]. However, there are few retrospective cohort studies that compare patients with confirmed COVID-19 to suspected cases through chest CT scans. Therefore, we conducted a retrospective cohort study to compare clinical characteristics and CT scan findings in suspected COVID-19 patients. Chest CT scans enable a rapid and detailed assessment of tissue and organ involvement in disease processes that are relevant to diagnosis and management, and so it is important to determine their usage for COVID-19, particularly since the outbreak of this coronavirus is seriously affecting people's lives worldwide.

Methods

Data Source

In this study, consecutively hospitalized patients with a suspected case of COVID-19 from January 21, 2020, to February 11, 2020, were identified at a single tertiary care referral hospital and followed up to the end of April 2020. In the absence of neutrophilia as an indicator of an alternative diagnosis of bacterial infection, patients were classified as suspected COVID-19 cases. Due to isolation care practices, all suspected COVID-19 patients were assessed in the fever clinic of the hospital. All suspected COVID-19 patients were included in this cohort study. Afterward, all suspected COVID-19 patients underwent physical examinations, including routine blood tests, C-reactive protein testing, SARS-CoV-2 nucleic acid examination, and chest CT scans. If the chest CT scan findings of a patient were abnormal according to the physician, while the result of nucleic acid examination was negative, then the patient underwent another nucleic acid examination. Positive patients who were then confirmed to be infected with SARS-CoV-2 by nucleic acid testing were transferred to a special ward for care.

Chest CT scans were performed using a GE Light Speed VCT 64-slice and Phillips Brilliance 16-slice CT. The scanning parameters used were as follows: tube voltage of 120 kV, automatic tube current, scanning layer thickness of 5.00 mm, reconstruction layer thickness of 11.5 mm, image reconstruction by high-resolution algorithm, and a matrix with $512 \times 512 = 262,144$ pixels. The lung window had a position of 500 Hounsfield units (HU) and a wider window width of 1500 HU. The mediastinum window had a position of 40 HU and a window width of 400 HU. Chest CT scans were focused on observing the density, number, distribution, location, and morphology of the lesions, as well as pleural thickening, pleural effusion, mediastinal lymph node enlargement, or other accompanying signs. In the early stages, one or two lungs had many shadows, and there were multiple ground glass density shadows. The internal lung texture was grid-like with halo signs around; the long axis of some lesions was parallel to the pleura and was not distributed according to lung segments. There was no cavity formation, no pleural effusion, and no significant swelling of mediastinal lymph nodes. There were also signs of bronchial ventilation. As the disease progresses, the diseased area rapidly increased and expanded, advancing from the periphery to the center along the bronchial vascular bundle, and may also be distributed in the form of antibutterfly wings. Therefore, we selected the following 12 CT indicators to better understand the imaging characteristics and severity of COVID-19: (1) location of lesions (ie, the left, right, or both lungs); (2) number of lesions; (3) location of the lesions along with the bronchus beam distribution, near pleural distribution, or mixed distribution; (4) lesion(s) size; (5) presence of the air bronchi sign; (6) presence of grid-like texture; (7) lesion morphology; (8) percentage of lung involvement; (9) presence of atelectasis; (10) whether the density of the lesion is ground-glass-like, solid, or mixed; (11) presence of pleural effusion, lymphadenopathy, or extrapulmonary manifestations;

and (12) other potential lung disease features such as pulmonary bullae, pulmonary nodules, calcifications, and fibrous lesions.

Study Design and Statistical Analysis

We divided all hospitalized patients with suspected COVID-19 in the cohort into either the positive group or the negative group based on the results of SARS-CoV-2 nucleic acid testing. One group was COVID-19 positive and the other group was COVID-19 negative. We wanted to compare patient epidemiological characteristics as well as clinical laboratory and CT scan findings in these two groups.

We summarized continuous variables as either means and standard deviations or medians with interquartile ranges for all patients in both the positive and negative groups. For categorical variables, we calculated the percentages of patients in each category. Characteristics for case and control patients were compared using the Student *t* test and analysis of variance, or nonparametric statistics (rank-sum tests) and chi-square tests as appropriate. An alpha of .05 was used as the cutoff for statistical significance. A LASSO (least absolute shrinkage and selection operator) logistic model for variable selection was used to identify the key predictors from all available variables. The area under the curve (AUC) with 95% CIs were calculated for each of the selected predictors, and the overall AUC of all these predictors was provided to show the most accurate combined variables for the biomarkers of COVID-19 from all available variables in the study. All analyses were done with SAS software, version 9.4 (SAS Institute Inc).

Ethics Statement

This was a retrospective case series study, and no patients were involved in the study design. Therefore, consent was waived.

Ethics approval for this project was obtained from the Institutional Review Board of the University of Nebraska Medical Center (IRB #1982933).

Results

Patient Epidemiological Characteristics

A total of 167 patients with a suspected case of COVID-19 were identified and included in the statistical analysis. Their basic characteristics are shown in [Table 1](#). Patients were aged 1-87 years with a mean age of 44 (SD 19) years; 92 (55%) were men and 75 (45%) were women. Of these initial 167 suspected COVID-19 cases, 94 (56%) were confirmed positive, and 38 (23%) had a history of traveling to Wuhan. Comorbidities varied; 23 (14%) patients had hypertension, 13 (8%) had diabetes, 13 (8%) had cardiogenic diseases, less than 5 (1%) had lung disease, less than 5 (1%) had kidney disease, and less than 5 (1%) had liver disease. Among 123 (74%) patients who exhibited symptoms, the most common symptoms were fever (n=123, 74%), cough (n=105, 63%), runny nose (n=22, 13%), gastrointestinal symptoms (n=22, 13%), sore throat (n=42, 25%), fatigue (n=32, 19%), and muscle pain (n=31, 19%). In total, 43 (26%) patients had been treated by Chinese medicine, which includes Lianhua Qingwen capsules and Jinhua Qinggan granules. Among the 94 patients who were confirmed COVID-19 positive, 2 (2%) patients were admitted to an intensive care unit (ICU) during this study. Both ICU patients were elderly individuals with hypertension or diabetes. No patients died during the study period.

Table 1. Epidemiological characteristics of suspected cases of COVID-19.

Characteristic	Total (N=167)	COVID-19 positive (n=94)	COVID-19 negative (n=73)	P value
Age (years), mean (SD)	44 (19)	47 (14)	38 (23)	
Age category (years) (%)				<.001
<18	11	1	23	
18-39	27	24	30	
40-59	45	57	29	
≥60	17	18	18	
Male (%)	55	60	50	.22
Travel history to Wuhan (%)	23	28	17	.04
Comorbidities (%)				
High blood pressure	14	16	13	.79
Diabetes	8	12	6	.26
Cardiogenic diseases	8	6	8	.88
Lung disease	1	1	0	N/A ^a
Anemic	0	0	0	N/A
Stroke	1	1	0	N/A
Kidney disease	0	0	0	N/A
Surgery	11	13	7	.94
Liver disease	0	0	0	N/A
First symptoms at admission (%)				
Fever	74	74	75	.65
Cough	63	73	55	.61
Runny nose	13	9	20	.23
Gastrointestinal symptoms	13	14	32	>.99
Sore throat	25	19	25	.48
Fatigue	19	18	18	>.99
Muscle pain	19	26	14	.08
Body temperature, mean (SD)	37.18 (0.79)	37.13 (0.82)	37.27 (0.78)	.07
Pulse, mean (SD)	90 (19)	84 (14)	92 (20)	.003
Respiratory rate, mean (SD)	19.72 (2.47)	19.13 (1.77)	20.25 (3.27)	.005
Blood pressure, mean (SD)	42 (2.13)	47 (14)	38 (23)	<.001
Medicine during the hospital (%)				
Antivirus	73	75	71	.64
Antibiotics	55	45	68	.002
Hormone	13	22	0	<.001
Chinese medicine ^b	26	47	0	<.001
Intensive care unit	1	2	0	N/A

^aN/A: not applicable.

^bRefers to Lianhua Qingwen capsules and Jinhua Qinggan granules.

Biochemical Testing

The results of clinical laboratory testing are summarized in [Table 2](#). C-reactive protein levels of the confirmed positive

patients (median 8.25, IQR 1.57-15.40) were significantly higher than those of confirmed negative patients (median 6.75, IQR 1.07-30.19). White blood cell count (median 4.89, IQR 4.05-5.68) was significantly lower in confirmed positive cases

compared to confirmed negative ones (median 7.99, IQR 5.08-10.03). Similarly, for red blood cell count, the confirmed positive group had a significantly lower value (median 4.49, IQR 4.03-4.90). Hemoglobin levels (median 134.20, IQR 108.11-149.23) of confirmed positive patients was significantly lower than confirmed negative patients (median 139.00, IQR 114.00-150.00).

Table 2. The results of routine blood tests from the clinical laboratory.

Routine blood tests	Total (N=167)	COVID-19 positive (n=94)	COVID-19 negative (n=73)	P value
C-reactive protein (mg/L), median (IQR)	7.10 (1.30-17.50)	8.25 (1.57-15.40)	6.75 (1.07-30.19)	<.001
White blood cell count ($10^9/L$), median (IQR)	5.38 (4.45-7.67)	4.89 (4.05-5.68)	7.99 (5.08-10.03)	<.001
Red blood cell count ($10^9/L$), median (IQR)	4.65 (4.09-5.00)	4.49 (4.03-4.90)	4.78 (4.40-5.08)	.002
Lymphocyte count ($10^9/L$), median (IQR)	1.16 (0.93-1.56)	1.30 (0.96-1.51)	1.11 (0.77-1.66)	.10
Hemoglobin (g/L), median (IQR)	137.24 (109.00-149.00)	134.20 (108.11-149.23)	139.00 (114.00-150.00)	.86
Platelet count ($10^9/L$), median (IQR)	142.00 (59.00-185.00)	145.1 (65.21-180.23)	134.00 (46.00-198.00)	.17
Plasma prothrombin time determination, median (IQR)	13.65 (13.00-13.90)	13.50 (13.10-13.81)	13.80 (10.80-15.15)	<.001
Thrombin time (second), median (IQR)	15.21 (14.45-15.76)	15.10 (14.43-15.70)	15.50 (14.50-16.10)	.54
Activated partial thromboplastin (second), median (IQR)	41.70 (40.00-45.80)	43.46 (40.10-45.60)	41.30 (38.00-46.80)	.003
D-D dimer ($\mu\text{g/ml}$), median (IQR)	0.45 (0.30-0.70)	0.40 (0.08-0.60)	0.70 (0.44-1.03)	.42
Alanine aminotransferase (IU/L), median (IQR)	28.70 (8.00-45.00)	33.00 (7.00-40.00)	25.50 (8.00-53.00)	.02
Urea nitrogen (mmol/L), median (IQR)	3.97 (3.39-4.90)	4.03 (3.43-4.66)	3.76 (3.15-6.19)	.19
Fibrinogen (g/L), median (IQR)	4.90 (4.06-5.67)	4.88 (4.07-5.67)	5.03 (3.31-5.90)	.69
Eosinophil count, median (IQR)	0.03 (0.01-0.09)	0.02 (0.01-0.07)	0.04 (0.01-0.11)	<.001
Hematocrit, median (IQR)	0.40 (0.37-0.44)	0.39 (0.36-0.42)	0.41 (0.38-0.45)	.005

Chest CT Scans and Imaging

In the first chest CT scan of the 167 patients with a suspected case of COVID-19, 80 (48%) of the confirmed positive patients had lesions in both of their lungs compared to 27 (30%) of the confirmed negative patients. Additionally, 73 (44%) patients in the positive group had more than three lesions compared to 28 (17%) patients in the negative group. Among the 94 confirmed positive cases, 89 (95%) had patch lesion morphology. The detailed comparative results are summarized in [Table 3](#).

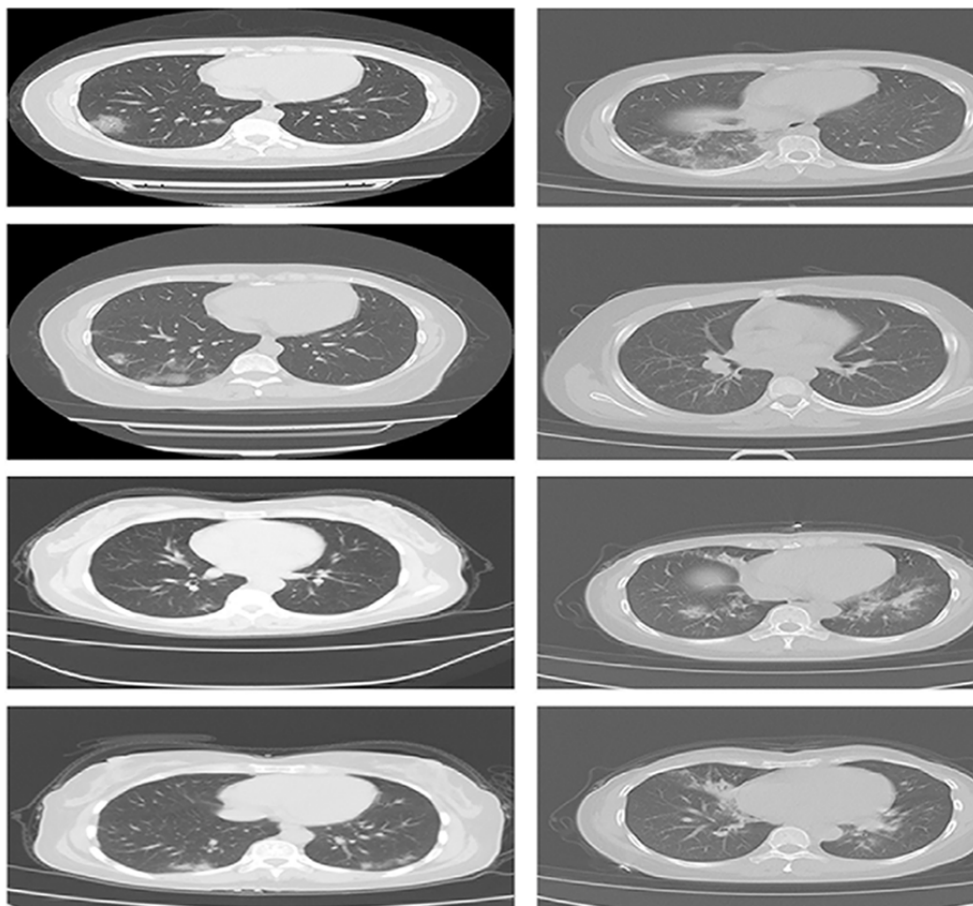
CT scans of 8 randomly selected patients are shown in [Figure 1](#). We found substantial, reliable differences in the chest CT scans of patients with COVID-19 from those who were suspected cases confirmed negative via nucleic acid testing. The dominant phenotype on the CT scan was the presence of multiple patchy lesions and a distribution of ground glass shadows in the peripheral pulmonary field, where denser lesions were large and strip-like with uneven density. Pleural thickening near affected lung segments was also seen in these patients.

Table 3. Chest computed tomography (CT) results with lesions and imaging manifestations.

CT image feature	COVID-19 positive (n=94)	COVID-19 negative (n=73)	P value
Distribution of lesions (%)			<.001
No lesions	0	1	
Left lung	6	27	
Right lung	9	42	
Both left and right lungs	85	30	
Number of lesions (%)			<.001
1	9	46	
2	9	16	
≥3	81	38	
Locations of lesions (%)			.01
Distributed along the bronchogram	11	15	
Close to the pleura	50	30	
Mixed distribution	39	55	
Size of lesion (cm) (%)			<.001
<1	11	37	
1-3	26	28	
>3	63	34	
Air bronchogram sign (%)			<.001
Yes	17	11	
No	83	89	
Lesions' internal texture (%)			<.001
Lattice texture	28	22	
No lattice texture	72	78	
Lesion morphology (%)			.003
Patch	95	37	
Pulmonary segments	2	26	
Lobe involvement	3	37	
Lung involvement (%)			<.001
<25%	59	73	
50%-75%	28	22	
>75%	16	5	
Atelectasis (%)			<.001
Yes	2	8	
No	98	91	
Lesion density (%)			.001
None	3	1	
Ground glass	23	19	
Solid	3	29	
Mixed	71	51	
Extrapulmonary manifestations (%)			<.001
Pleural effusion	3	1	
Lymphadenopathy	3	12	

CT image feature	COVID-19 positive (n=94)	COVID-19 negative (n=73)	P value
None	94	87	
Other lung diseases including bullae, pulmonary nodule, fibrous stove, calcification, and tuberculosis (%)			<.001
Yes	33	22	
No	67	78	

Figure 1. The images in the left panel are CT scans of four randomly selected confirmed COVID-19–positive patients. There are multiple patchy lesions, and the grinding glass shadows are distributed in the peripheral pulmonary field. The images in the right panel are CT scans of four randomly selected suspected patients who were confirmed to be COVID-19 negative. Their lesions are large, strip-like, and have uneven density. Pleural thickening near affected lung segments is also seen.



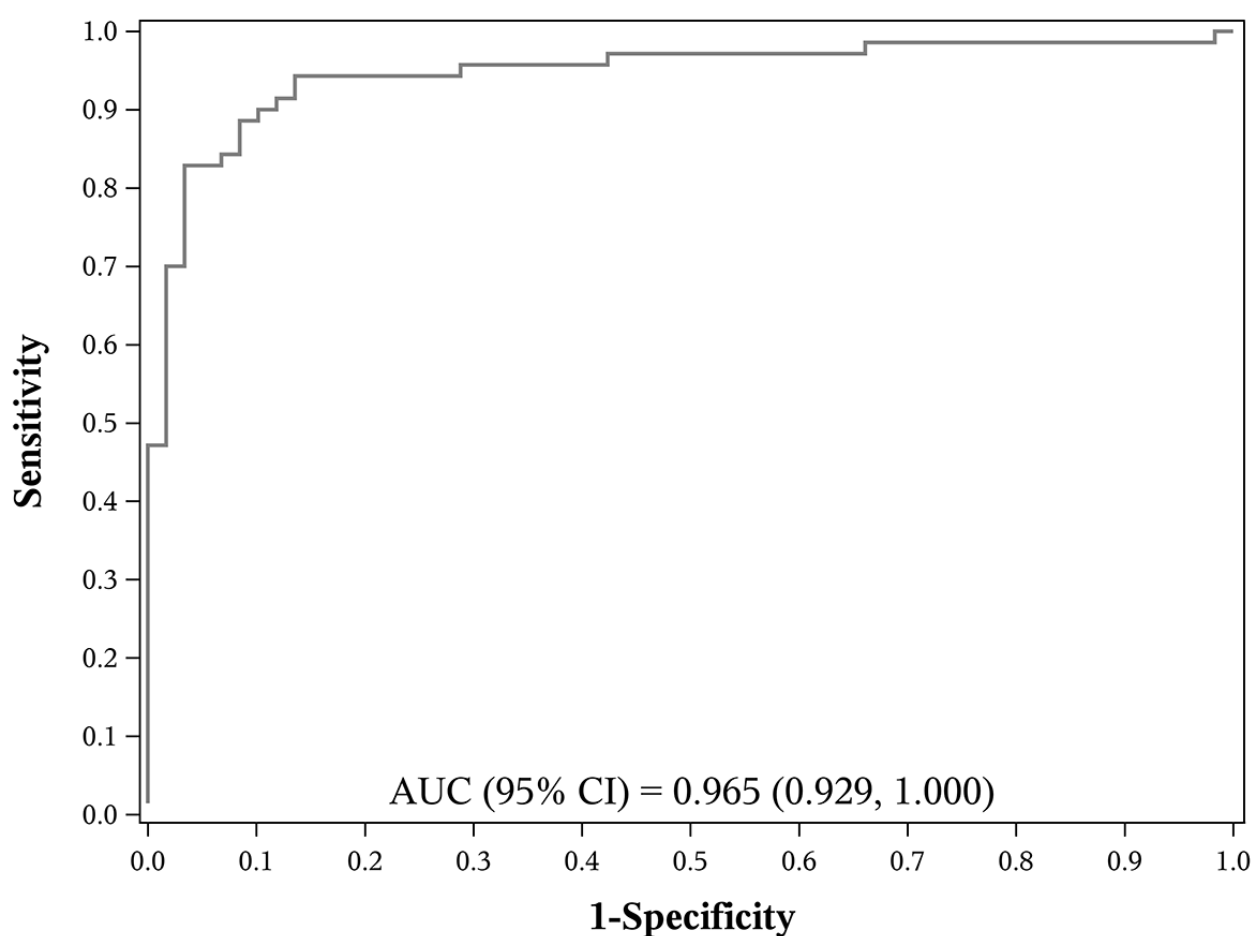
Multivariable Analysis

A multivariable LASSO logistic model for variable selection was used to identify the key predictors from all variables in Tables 1-3. We found the key predictors for COVID-19 to be white blood cell count, lesion morphology, distribution of

lesions, cough, locations of lesions, and travel history to Wuhan. The AUC for each of the selected predictors ranged from 0.56 to 0.80, as shown in Table 4. The overall AUC of all these selected key predictors was 0.97 (95% CI 0.93-1.00), as shown in Figure 2.

Table 4. Area under the curve (AUC) values for the selected predictors from the logistic model with LASSO (least absolute shrinkage and selection operator) selection.

Selected variables	AUC (95% CI)
White blood cell count	0.80 (0.72-0.87)
Lesion morphology	0.78 (0.71-0.84)
Distribution of lesions	0.76 (0.69-0.84)
Cough	0.59 (0.52-0.66)
Locations of lesions	0.56 (0.47-0.65)
Travel history to Wuhan	0.55 (0.48-0.61)
Overall AUC of the above selected variables	0.97 (0.93-1.00)

Figure 2. The receiver operating characteristic (ROC) curve of selected variables for COVID-19–positive cases. The ROC curve demonstrates the trade-off between sensitivity and specificity, and shows that the biomarker with a combination of selected variables is the most accurate test for identifying patients with COVID-19 due to an area under the curve (AUC) value of 0.97 (95% CI 0.93-1.00).

Discussion

This retrospective cohort study described the differences in clinical characteristics between patients who were confirmed COVID-19 positive to those confirmed to be COVID-19 negative. Elderly people were more likely to be infected by COVID-19. We also found significant associations between low white blood cell count, high C-reactive protein, and a subsequent positive COVID-19 test. Regarding the low white blood count, this is common in viral infections and is of a larger magnitude than the absence of leukocytosis. Fever symptoms

are the first clinical characteristics, alongside gastrointestinal reactions, sore throat, fatigue, and muscle pain. However, many patients (n=24, 26%) did not have a fever and cough. Of the original 167 suspected patients, 6 (4%) were negative according to the results of their first nucleic acid test, but they were consequently confirmed positive after performing CT chest scans. Chest CT scans can supply a better understanding of COVID-19, especially for patients with no specific symptoms, such as fever and cough.

While other studies have begun to describe clinical experiences of this novel disease, our patients had not yet been described

nor this question addressed [7]. For example, laboratory examination showed normal or decreased peripheral white blood cells, and CT scan findings showed that the locations of lesions are more likely to be close to the pleura. Compared with the clinical outcomes of other studies [8-11], fewer patients (less than 5%) were admitted to an intensive care unit in our study, and no patients died during the study period. More importantly, few studies have provided a comparison of patients who were confirmed COVID-19 positive to those who were confirmed COVID-19 negative. Therefore, one strength of this paper is that we can clearly show the differences between confirmed positive and confirmed negative patients through our retrospective cohort design. The comparative results can provide some valuable information in the understanding of the clinical features of COVID-19 to help identify patients who have the coronavirus from a large group of patients who may or may not be infected. This is especially applicable to current times since the number of people suspected to be infected with the disease is increasing rapidly worldwide. Another strength of this paper is that we could identify the top key predictors from all predictors based on the multivariable LASSO logistic model. The area under the multivariable receiver operating characteristic (ROC) curve (0.97, 95% CI 0.93-1.00) illustrates that the combined biomarker of these selected key predictors is a good

index for COVID-19. However, this study has some inherent limitations as a retrospective cohort study. For example, we did not have additional laboratory or lung function data to measure immune responses. This retrospective study lacks a formal sample size and power calculations. The power of this study may be limited due to the relatively small number of infected patients with chest CT scans; the study also took place at a single tertiary care referral hospital. The results need to be replicated with a larger number of COVID-19-confirmed cases in future studies.

With our well-characterized patients, this retrospective cohort study can enhance our understanding of the use of chest CT scans for COVID-19 case management. For example, we found that the early signs of CT lesions are in both lungs, and locations of lesions are more likely to be close to the pleura. We also observed that the lesion distribution gradually expands from the periphery to the center, and the lesion density is more inclined to be mixed. Therefore, chest CT scans should be more broadly adopted along with nucleic acid testing in the initial assessment of suspected COVID-19 cases when the nucleic acid examination is delayed or negative, or when further clinical characterization of severity is needed, especially for patients with nonspecific symptoms.

Conflicts of Interest

None declared.

References

1. Lu H, Stratton C, Tang YW. Outbreak of pneumonia of unknown etiology in Wuhan, China: The mystery and the miracle. *J Med Virol* 2020 Apr;92(4):401-402 [FREE Full text] [doi: [10.1002/jmv.25678](https://doi.org/10.1002/jmv.25678)] [Medline: [31950516](https://pubmed.ncbi.nlm.nih.gov/31950516/)]
2. Clinical management of severe acute respiratory infection when novel coronavirus (nCoV) infection is suspected: interim guidance, 12 January 2020. World Health Organization. 2020 Jan 12. URL: <https://apps.who.int/iris/handle/10665/332299> [accessed 2020-10-05]
3. Chan JF, Yuan S, Kok K, To KK, Chu H, Yang J, et al. A familial cluster of pneumonia associated with the 2019 novel coronavirus indicating person-to-person transmission: a study of a family cluster. *The Lancet* 2020 Feb;395(10223):514-523 [FREE Full text] [doi: [10.1016/s0140-6736\(20\)30154-9](https://doi.org/10.1016/s0140-6736(20)30154-9)]
4. Zhou Y, Dong J. Statistical Inference for Coronavirus Infected Patients in Wuhan. Preprint. medRxiv 2020 Feb 12:e [FREE Full text] [doi: [10.1101/2020.02.10.20021774](https://doi.org/10.1101/2020.02.10.20021774)]
5. Li N, Han L, Peng M, Lv Y, Ouyang Y, Liu K, et al. Maternal and neonatal outcomes of pregnant women with COVID-19 pneumonia: a case-control study. *Clin Infect Dis* 2020 Mar 30:a [FREE Full text] [doi: [10.1093/cid/ciaa352](https://doi.org/10.1093/cid/ciaa352)] [Medline: [32249918](https://pubmed.ncbi.nlm.nih.gov/32249918/)]
6. Beltrán-Corbellini Á, Chico-García JL, Martínez-Poles J, Rodríguez-Jorge F, Alonso-Cánovas A. Acute - onset smell and taste disorders in the context of COVID - 19: a pilot multicentre polymerase chain reaction based case-control study. *Eur J Neurol* 2020;27(9):1738-1741 [FREE Full text] [doi: [10.1111/ene.14273](https://doi.org/10.1111/ene.14273)]
7. Wang W, Tang J, Wei F. Updated understanding of the outbreak of 2019 novel coronavirus (2019-nCoV) in Wuhan, China. *J Med Virol* 2020 Apr;92(4):441-447 [FREE Full text] [doi: [10.1002/jmv.25689](https://doi.org/10.1002/jmv.25689)] [Medline: [31994742](https://pubmed.ncbi.nlm.nih.gov/31994742/)]
8. N/A. Clinical findings in a group of patients infected with the 2019 novel coronavirus (SARS-Cov-2) outside of Wuhan, China: retrospective case series. *BMJ* 2020 Feb 27;368:m792. [doi: [10.1136/bmj.m792](https://doi.org/10.1136/bmj.m792)] [Medline: [32107200](https://pubmed.ncbi.nlm.nih.gov/32107200/)]
9. Wang D, Hu B, Hu C, Zhu F, Liu X, Zhang J, et al. Clinical Characteristics of 138 Hospitalized Patients With 2019 Novel Coronavirus-Infected Pneumonia in Wuhan, China. *JAMA* 2020 Mar 17;323(11):1061-1069 [FREE Full text] [doi: [10.1001/jama.2020.1585](https://doi.org/10.1001/jama.2020.1585)] [Medline: [32031570](https://pubmed.ncbi.nlm.nih.gov/32031570/)]
10. Huang C, Wang Y, Li X, Ren L, Zhao J, Hu Y, et al. Clinical features of patients infected with 2019 novel coronavirus in Wuhan, China. *The Lancet* 2020 Feb;395(10223):497-506. [doi: [10.1016/s0140-6736\(20\)30183-5](https://doi.org/10.1016/s0140-6736(20)30183-5)]
11. Guan W, Ni Z, Hu Y, Liang W, Ou C, He J, China Medical Treatment Expert Group for Covid-19. Clinical Characteristics of Coronavirus Disease 2019 in China. *N Engl J Med* 2020 Apr 30;382(18):1708-1720 [FREE Full text] [doi: [10.1056/NEJMoa2002032](https://doi.org/10.1056/NEJMoa2002032)] [Medline: [32109013](https://pubmed.ncbi.nlm.nih.gov/32109013/)]

Abbreviations

AUC: area under the curve
CT: computed tomography
HU: Hounsfield unit
ICU: intensive care unit
LASSO: least absolute shrinkage and selection operator
MERS: Middle East respiratory syndrome
ROC: receiver operating characteristic
SARS: severe acute respiratory syndrome

Edited by T Sanchez; submitted 16.04.20; peer-reviewed by A Phillips, R Joseph; comments to author 05.08.20; revised version received 21.08.20; accepted 09.09.20; published 20.10.20.

Please cite as:

Wu L, Jin Q, Chen J, He J, Brett-Major DM, Dong JJ

Diagnostic Accuracy of Chest Computed Tomography Scans for Suspected Patients With COVID-19: Receiver Operating Characteristic Curve Analysis

JMIR Public Health Surveill 2020;6(4):e19424

URL: <http://publichealth.jmir.org/2020/4/e19424/>

doi: [10.2196/19424](https://doi.org/10.2196/19424)

PMID: [33001830](https://pubmed.ncbi.nlm.nih.gov/33001830/)

©Lianpin Wu, Qike Jin, Jie Chen, Jiawei He, David M Brett-Major, Jianghu James Dong. Originally published in JMIR Public Health and Surveillance (<http://publichealth.jmir.org>), 20.10.2020. This is an open-access article distributed under the terms of the Creative Commons Attribution License (<https://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in JMIR Public Health and Surveillance, is properly cited. The complete bibliographic information, a link to the original publication on <http://publichealth.jmir.org>, as well as this copyright and license information must be included.

Original Paper

Social Media as an Early Proxy for Social Distancing Indicated by the COVID-19 Reproduction Number: Observational Study

Joseph Younis^{1*}, BSc; Harvy Freitag^{1*}, BSc; Jeremy S Ruthberg¹, BA; Jonathan P Romanes², BSc; Craig Nielsen³, MD; Neil Mehta³, MBBS, MS, MD

¹Case Western Reserve School of Medicine, Cleveland, OH, United States

²Kansas City University of Medicine and Biosciences, Kansas, MO, United States

³Department of Internal Medicine and Geriatrics, Cleveland Clinic Foundation, Cleveland, OH, United States

*these authors contributed equally

Corresponding Author:

Joseph Younis, BSc

Case Western Reserve School of Medicine

Health Education Campus

9501 Euclid Ave

Cleveland, OH, 44106

United States

Phone: 1 630 407 4703

Email: jxy641@case.edu

Abstract

Background: The magnitude and time course of the COVID-19 epidemic in the United States depends on early interventions to reduce the basic reproductive number to below 1. It is imperative, then, to develop methods to actively assess where quarantine measures such as social distancing may be deficient and suppress those potential resurgence nodes as early as possible.

Objective: We ask if social media is an early indicator of public social distancing measures in the United States by investigating its correlation with the time-varying reproduction number (R_t) as compared to social mobility estimates reported from Google and Apple Maps.

Methods: In this observational study, the estimated R_t was obtained for the period between March 5 and April 5, 2020, using the EpiEstim package. Social media activity was assessed using queries of “social distancing” or “#socialdistancing” on Google Trends, Instagram, and Twitter, with social mobility assessed using Apple and Google Maps data. Cross-correlations were performed between R_t and social media activity or mobility for the United States. We used Pearson correlations and the coefficient of determination (ρ) with significance set to $P < .05$.

Results: Negative correlations were found between Google search interest for “social distancing” and R_t in the United States ($P < .001$), and between search interest and state-specific R_t for 9 states with the highest COVID-19 cases ($P < .001$); most states experienced a delay varying between 3-8 days before reaching significance. A negative correlation was seen at a 4-day delay from the start of the Instagram hashtag “#socialdistancing” and at 6 days for Twitter ($P < .001$). Significant correlations between R_t and social media manifest earlier in time compared to social mobility measures from Google and Apple Maps, with peaks at -6 and -4 days. Meanwhile, changes in social mobility correlated best with R_t at -2 days and +1 day for workplace and grocery/pharmacy, respectively.

Conclusions: Our study demonstrates the potential use of Google Trends, Instagram, and Twitter as epidemiological tools in the assessment of social distancing measures in the United States during the early course of the COVID-19 pandemic. Their correlation and earlier rise and peak in correlative strength with R_t when compared to social mobility may provide proactive insight into whether social distancing efforts are sufficiently enacted. Whether this proves valuable in the creation of more accurate assessments of the early epidemic course is uncertain due to limitations. These limitations include the use of a biased sample that is internet literate with internet access, which may covary with socioeconomic status, education, geography, and age, and the use of subtotal social media mentions of social distancing. Future studies should focus on investigating how social media reactions change during the course of the epidemic, as well as the conversion of social media behavior to actual physical behavior.

KEYWORDS

COVID-19; social media; Google Trends; Twitter; Instagram; reproduction number; estimated reproduction number; social distancing; public health surveillance; social media surveillance; Google Maps; Apple Maps; pandemic; epidemic

Introduction

Public health measures are the epicenter of global efforts to combat the COVID-19 pandemic [1]. The premise of these measures converges on a central notion: decreasing the basic reproductive number (R_0) of the novel coronavirus below 1 to suppress transmission. With an R_0 value below 1, the virus can no longer sustainably propagate from one person to another, eventually halting its spread [2]. The most championed of these efforts is the idea of “social distancing,” or the practice of distancing yourself from others to reduce respiratory droplet transmission, the primary mode of transmission for COVID-19 [3]. However, social distancing has not been inconsequential, with primary concern to socioeconomic health. Several macroeconomic reports exploring the supply and demand shock of COVID-19 describe that its effects may rival that of the 1918 Spanish Flu and the Great Depression [4].

Transmission of COVID-19 was first detected in the United States on February 2020, and by mid-March, all 50 states and four US territories had reported cases of COVID-19 [5]. The total number of confirmed cases continued to rise exponentially before this trend was broken in early April. In an effort to slow transmission, several states implemented strict lockdowns, curfews, and business restrictions [6]. New York Governor Cuomo declared a state of emergency on March 7, and New York City implemented one of the first large-scale lockdowns of schools, temples, and other large gathering places in Rochelle. This further extended to include stay-at-home orders in other areas of New York, California, and Illinois. Restrictions on businesses deemed nonessential were eventually implemented in more than 40 states [6].

In response, decreases across several economic sectors have been witnessed, leading to financial strain on American households. Over 10 million unemployment claims were filed in the 2 weeks ending on March 28, 2020 [7]; for reference, the previous peak was at 695,000 claims in October 1982. National-level interventions such as mandated paid time off and a historic US \$2 trillion stimulus package (Coronavirus Aid, Relief, and Economic Security Act) were used to mitigate the broad impact of COVID-19 [8].

Early intervention is ideal for the mitigation of a pandemic’s socioeconomic and health costs, but such potential is often a post hoc discovery. A more practical approach is active scrutiny and revision of the implemented measures, ideally in the early phases of the pandemic’s course [9]. Recent efforts have attempted to quantify social distancing efforts using Google or Apple Maps’ user activity [10,11]. Although these tools accurately reflect social behavior at a point in time, we hypothesize that Google Trends and social media yield earlier actionable insight that can help control the pandemic’s trajectory.

Google Trends and social media (eg, Instagram and Twitter) are used extensively in the scientific literature and have been validated against external reference data sets in numerous public health and health surveillance studies [12-17]. With an estimated 35% and 27% of all US citizens using Instagram and Twitter, respectively, on a regular basis and 89.7% of digital users searching on Google, these avenues remain the most practical tools for study [18-20]. Likewise, studies during this pandemic are investigating the utility of social media in the dissemination of preventive health information [21-23], and Twitter recently provided full access for prospective social media data tracking for COVID-19 research. Despite this, their use as epidemiological tools in the assessment of social behavior in early epidemic courses remains to be determined.

In this study, we investigate the use of Google Trends, Instagram, and Twitter as tools for the evaluation of social distancing measures by the public in the early epidemic phase. We first highlight a correlation between social distancing measures as captured by social media and national and state-specific time-varying reproduction number (R_t), an epidemiological estimate of R_0 throughout an epidemic. We then compare the correlation of these social media avenues with R_t to the correlation of Google and Apple Maps’ user activity with R_t . We focused on the top nine affected states from the time of writing, April 10, 2020. We collected the most recent social media data using Google Trends, Twitter, and Instagram, and used the updated confirmed cases compiled by the Centers of Disease Control COVID-19 Case Data and John Hopkins Coronavirus Resource Center [24,25].

Methods

Database Inclusion

We used Google Trends, Instagram, and Twitter. In addition to their established use in the scientific literature, we also focused on Instagram and Twitter because their demographic overlaps significantly with the public-facing jobs [18-20] most likely to be affected by social distancing. Furthermore, a poll conducted by the Morning Consult between March 27 and 30, 2020, reported 88% of Americans between the ages of 30-54 years are practicing social distancing to some extent [20,26], an age range closely resembling Instagram and Twitter’s median ages of 34 and 40, respectively.

The choice to include only the top nine states by COVID-19 incidence was made because lower incidence states yielded insufficient social media and incidence data. When the analysis was run on the bottom nine states by COVID-19 incidence, the results displayed erratic patterns of social distancing search interest with no clear peak and days with no data, suggesting low search volumes; additionally, the R_t displayed large error

margins and could not be calculated continuously over the study period.

Google Trends

Google Trends records billions of data points from search terms entered by the public. It then compares the summative search volume of each search query (defined as the exact term entered into Google's search bar) to the day of highest search volume to yield a search volume index (SVI) score of 1-100. SVI is assigned to each day and represents that day's relative search frequency. Google Trends contains a geo-filtering feature that allows search data from within the United States or, to be more granular, from specific states.

Google Trends data for the search query "Social Distancing" was collected on April 10, 2020, for March 1, 2020, through April 10, 2020.

Instagram and Twitter

Instagram and Twitter are social networking platforms that can be accessed on a phone app or internet website. As of 2018, there are 107 million Instagram users in the United States. Similarly, as of January 2020, 59 million Twitter users are American, comprising the largest percentage of Twitter's user base. Together, these social networking services capture a large percentage of the American population [20,26].

Unamo search algorithms were used to capture the historical frequency of mentions for the hashtag "#socialdistancing" in the United States on Twitter and Instagram between March 1 and April 10, 2020 [27].

Calculation of R_t

R_0 is the number of individuals infected by a single infected individual during his or her entire infectious periods in a population that is entirely susceptible.



Where κ is the rate at which an exposed individual becomes infectious, β is the probability that a susceptible individual becomes infected upon interaction with an infected individual, λ is the birth rate of susceptible individuals, μ is the per capita natural death rate, and γ is the per capita recovery rate.

The R_0 for COVID-19 has varied in value from 1.4 to as high as 11.1 reported from some communities in China and Singapore [28,29].

The R_t is an epidemiological estimate of R_0 calculated using two variables: (1) the daily incidence of acute respiratory illness onset and (2) the distribution of the serial interval (time interval between symptoms onset in a case and in their infector).

The daily incidence of COVID-19 in the United States was obtained from estimations of symptom onset provided by the Centers for Disease Control and Prevention COVID-19 Case Data, which contains data up to April 5, 2020 [24]. The statewide incidence rate is based on confirmed cases obtained from the John Hopkins Coronavirus Resource Center. The serial interval was obtained using available parametric data computed previously for the initial outbreak of COVID-19 [30].

We used the R statistical software (R Foundation for Statistical Computing) along with the EpiEstim package to calculate the R_t using the aforementioned parameters for the period of March 5 to April 5, 2020. R_t for the United States and top nine states by confirmed COVID-19 cases was derived for this time period. For subsequent calculations, we included data after the onset of at least 100 confirmed cases in each state, as the R_t prior to that had standard deviations in excess of 0.5.

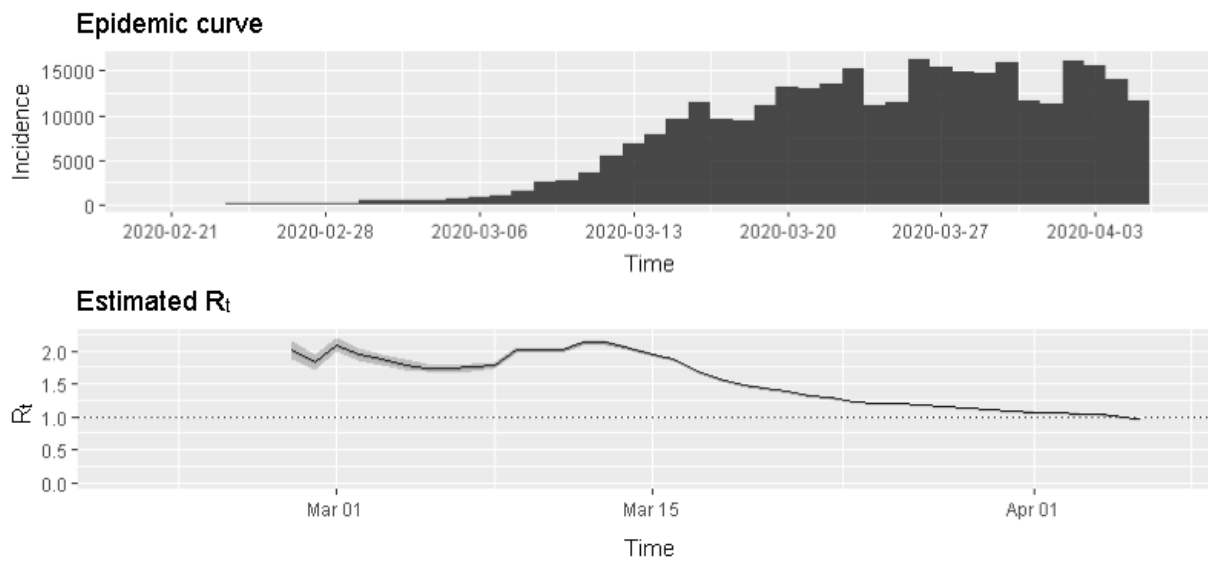
The Google Trends SVI for "social distancing" was then independently compared to R_t for the top nine affected states (New York, California, Pennsylvania, Massachusetts, New Jersey, Florida, Louisiana, Michigan, and Illinois) and the United States as a whole. Analyses were performed using Pearson correlations with significance set to $\alpha < .05$ then plotted on logarithmic graphs. Correlations were obtained using raw data and after varying periods of time delay between the Google SVI or social media mentions and changes in R_t .

Cross-correlations for the relationship between R_t and measures of social distancing in the United States were performed, using available data based on Google Maps tracking that measures changes in percent social mobility. This data was available for separate locations, including grocery and pharmacy stores, recreation and retail stores, and workplaces. In addition, the cross-correlations between R_t and "#socialdistancing" mentions on Instagram and Twitter were also performed. The coefficient of determination (ρ^2) was calculated and graphed, which represents the strength of the correlation at different time delays between R_t and each of the social mobility and social media measures. The peak of the coefficient of determination for each of these measures were tabulated along with the delay for which the greatest strength of relationship was found.

Results

In Figure 1, the estimated R_t is shown for the period of February 28 to April 5, 2020, calculated from the number of COVID-19 cases by symptom onset, with a mean serial interval of 3.96 (SD 4.75) days. The shaded error bands are equal to 1 SD of the estimated R_t for each date.

Figure 1. The time-variant or effective reproduction number (R_t) represents the mean number of secondary cases generated by a primary case over a sliding weekly window. The estimated R_t is shown for the period of February 28 to April 5, 2020, calculated from the number of COVID-19 cases by symptom onset, with a mean serial interval of 3.96 days and SD of 4.75 days. The shaded error bands are equal to 1 SD of the estimated R_t for each date.



Significant negative correlations were found between the Google SVI for the search query “social distancing” and the R_t between the dates of March 5 and April 5, 2020, in the United States ($P < .001$). The relationship between estimated R_t and Google SVI is visualized graphically in Figure 2a. The strength of the correlation reached a peak at 4 days delay from the start of the searches when considering all cases in the United States, with a Pearson correlation coefficient of 0.72 ($P < .001$).

There was a total of 376,067 “#socialdistancing” mentions on Instagram and 6470 on Twitter in the studied time period. The increase in “#socialdistancing” mentions on Twitter and Instagram predate the appearance of a decrease in R_t seen in Figure 2b and c. The relationship between R_t and Instagram mentions (Figure 2c) is significant and strongest at a 4-day delay ($P < .001$) from the start of Instagram hashtag “#socialdistancing” mentions. Significance for Twitter is seen only at a 6-day delay ($P < .001$).

When evaluated by state, New York, New Jersey, Massachusetts, Michigan, Pennsylvania, California, Louisiana, Illinois, and Florida all showed significant negative correlations between “social distancing” SVI and the state-specific R_t ($P < .001$; refer to Figure 3). These correlations reached peak significance at different delay periods. R_t for some states such as Massachusetts experienced an early correlation with increasing searches for “social distancing.” Other states such as New York and Louisiana experienced a larger time delay from the start of Google searches to a decrease in R_t at 6 and 8 days, respectively. Most states experienced a delay varying between 3-8 days before reaching peak significance.

Significant correlations between R_t and social media appear to manifest themselves earlier in time when compared to social mobility measures, with peaks at -6 and -4 days for the relationship between R_t and Twitter and Instagram mentions, respectively ($P < .001$; refer to Figure 4). Social mobility correlated best with R_t at -2 days and +1 day for workplace and grocery/pharmacy, respectively.

Figure 2. The left-most graph (a) shows the relationship between Google Trends search volume index (SVI) for “social distancing” and estimated R_t for the United States over the time period from March 5 to April 5, 2020. The light blue line represents the Google SVI and the dark grey line represents the estimated R_t . The middle and right-most graphs show the relationships between estimated R_t and total social media mentions for “#socialdistancing” on (b) Instagram and (c) Twitter over the same time period. Light blue lines refer to total number of mentions for “#socialdistancing” and dark grey lines represent the estimated R_t . Error bands shown in light gray shading represent 1 SD from the mean R_t calculated at each date. R_t : time-varying reproduction number.

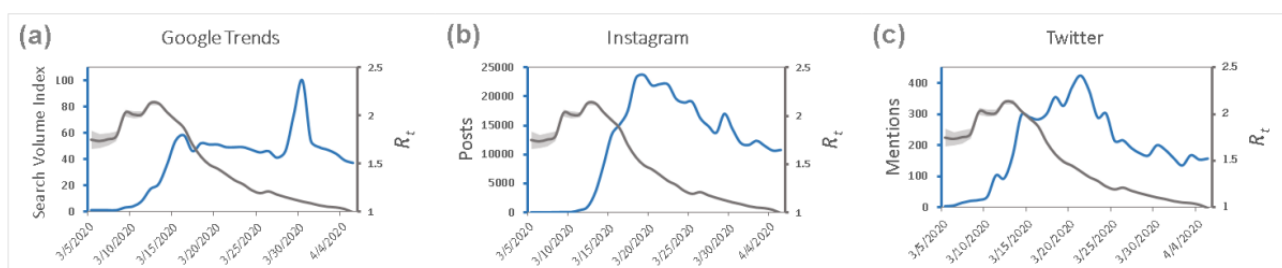


Figure 3. The estimated R_t was calculated individually for the top 9 states with the most confirmed COVID-19 cases on April 5, 2020. They are graphed for the period of March 5 to April 5 for each state (dark line) along with the Google search index for “social distancing” in each state for the same time period (light blue bars). Error bands represent 1 SD from the mean estimated R_t at each date. R_t : time-varying reproduction number; SVI: search volume index.

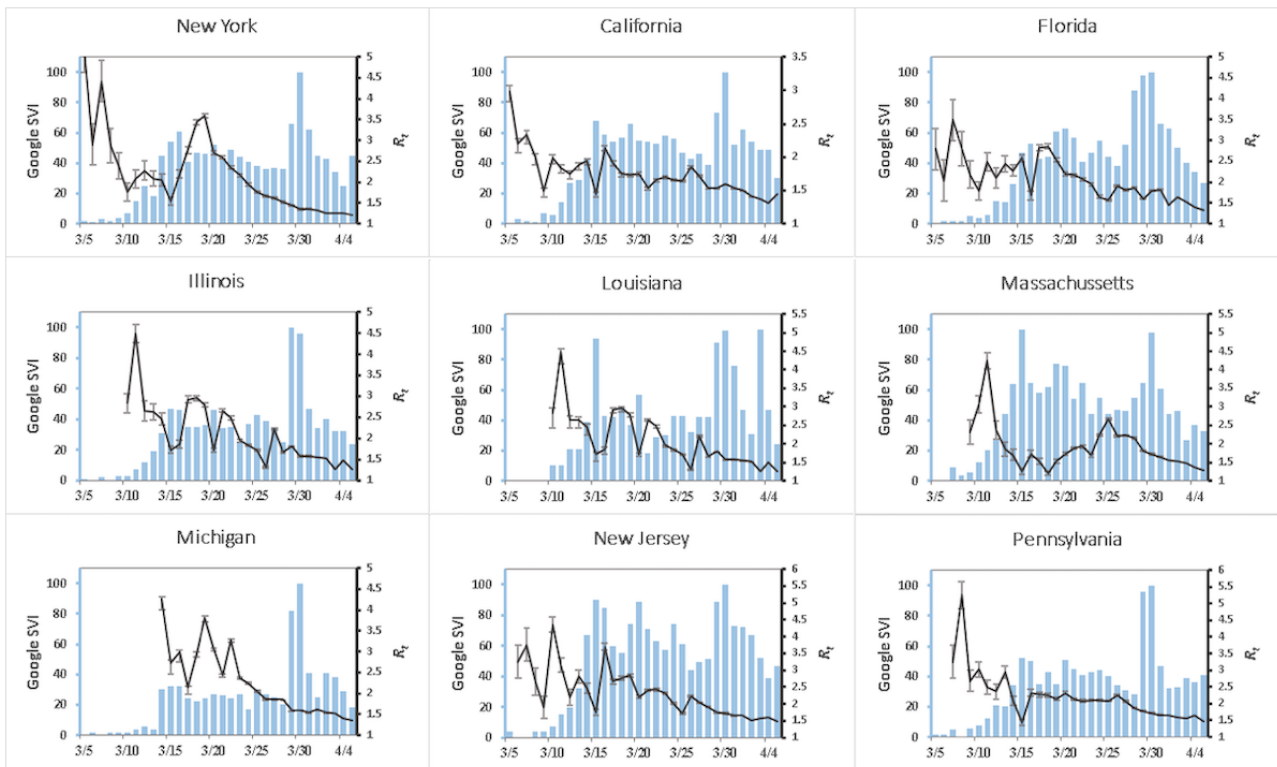
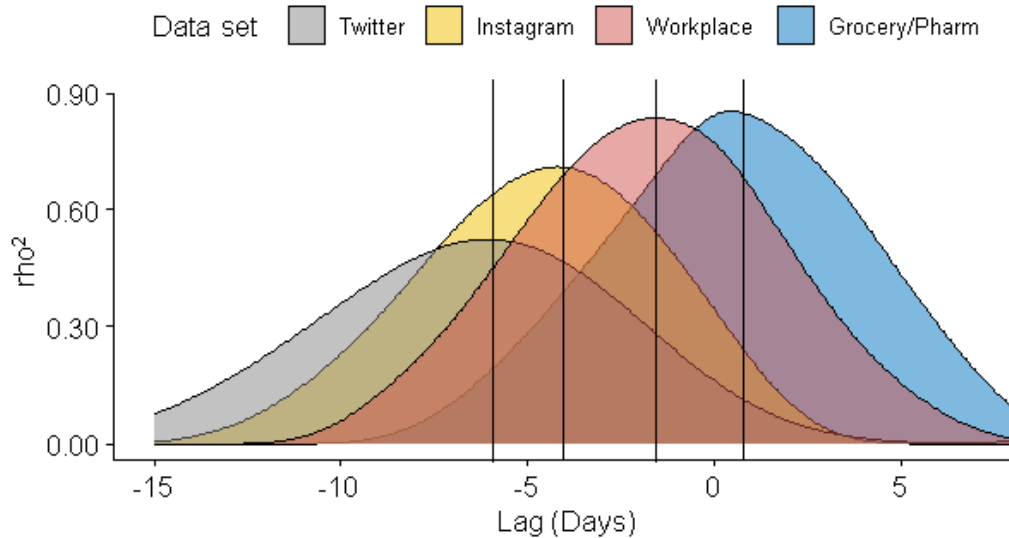


Figure 4. Cross-correlations (represented by ρ^2 , the coefficient of determination) between estimated R_t and social mobility changes, and social media mentions in the United States. The black lines represent the peak correlation. Social mobility changes include traffic at grocery, pharmacy, and workplace locations based on Google Maps tracking. Social media measures include mentions of “#socialdistancing” on Instagram and Twitter. Pharm: pharmacy; R_t : time-varying reproduction number.



The relationship between R_t and social media or social mobility ($P < .001$) reaches its strongest point at different delay periods, tabulated in Table 1. The increase in social media mentions predates the decrease in R_t the earliest, with a lag time of 4-6 days. Social mobility data also predate the decrease in R_t , although at later times of 0-3 days. Table 1 also shows the strength of correlation between each of the measures and R_t ,

represented by ρ^2 . The strongest correlations are between social mobility data and R_t with comparatively lower correlations between social media and R_t . Google Trends, however, shows a comparable ρ^2 with data from Apple Maps but not Google Maps, which exhibits the strongest correlations for all domains except parks.

Table 1. Peak correlations between social media and social mobility measures and associated time delay

Data set	ρ^2	Lag (days)
Social media		
Instagram	0.68	-4
Twitter	0.47	-6
Google Trends	0.72	-4
Apple Maps		
Driving	0.75	-3
Transit	0.80	-3
Walking	0.73	-2
Google Maps		
Grocery/pharmacy	0.89	+1
Transit	0.83	-2
Workplace	0.86	-2
Parks	0.66	-2
Recreation	0.84	0
Residential	0.85	-2

Discussion

Principal Findings

In our study, we found that increased social distancing mentions on social media correlated with reduced US R_t , with Google Trends correlating with reduced state-specific R_t as well. We also found that the correlation varied when social distancing mentions or search queries were lagged by a few days; this effect depended on the state and social media platform. The delay to reach peak strength discrepancy between Instagram and Twitter is interesting because the reach of Instagram in the United States is much greater, indicating possible time-sensitive influence on behavior imparted by user reach. Why the delay periods differed between states is unclear but may be partly explained by the unequal implementation of top-down public health interventions.

Instagram and Twitter mentions of “#socialdistancing” correlated earlier with reduced COVID-19 R_t in the United States than did social mobility measures from Google and Apple Maps. Interestingly, Twitter showed the earliest correlation with R_t but also has the lowest coefficient of determination. This finding may be explained by the fact that Twitter reaches the smallest user base compared to Instagram or Google Maps. Social media in general exhibited a weaker correlation with R_t . This is expected since social mobility measures directly relate to the density of people congregating in an area, whereas social media is an indirect measure of social distancing and likely represents a smaller proportion of the population. Nonetheless, these findings confirm our hypothesis that social media may serve as earlier indicators of future social behavior.

The idea that lagging social distancing efforts as captured by social media produces significant reductions in R_t implicates a predictive role for social media. This is consistent with the

interpretation that Google Trends, Instagram, and Twitter model the dissemination of information that may lead to individual decisions to undergo social distancing. Although the strength of the correlation for social media was found to be weaker than that for social mobility, the value was in the relationship of the correlation to time. Furthermore, the strength of the correlation may improve with subsequent studies using more accurate measures of social distancing in the media to actual social distancing behavior in the public.

An additional interpretation for the significance found in lagging social media mentions is that the delayed drop in R_t is also consistent with the expectation that social distancing is a method of primary prevention, as early practice prevents a future increase in R_t . It is tempting to consider whether these effects depend on the incubation period for COVID-19. About 50% of infected individuals show symptoms by 5 days, and 97.5% by 12 days [2,31]. Our study shows that all 9 states exhibited a significantly reduced R_t with an 8-day lag period for social distancing search interest, supporting a quarantine time frame that confidently covers the upper limit of the incubation period. On the contrary, quarantine times closer to the median incubation period of COVID-19 may be insufficient, as only 30% of the states showed significant reductions in R_t when the lag period was shorter than the median incubation period. A parallel can be drawn from these findings, albeit speculatively: there may also be a threshold in this pandemic’s trajectory in the United States before which a termination of social distancing efforts may be too early.

Limitations

Whether this proves valuable in the creation of more accurate assessments of the early epidemic course is uncertain due to limitations. Limitations of this study are inherent to the use of Google Trends, Instagram, and Twitter because they are

presumably indirect measures of public behavior. The data represents a subtotal amount of mentions on Instagram and Twitter, and the study period is short and during the early course of the epidemic where testing and reporting COVID-19 was imperfect. Additionally, we focused on only the top nine states by incidence; although this was an effort to reduce false-positive findings from unreliable low-incidence states, it does introduce barriers to generalizing results to other states. Furthermore, social media may represent a biased sample of those that are internet literate and with access to internet, which may effectively covary with socioeconomic status, education, geography, and age.

Conclusion

Our study demonstrates the utility of Google Trends, Instagram, and Twitter as epidemiological tools in the assessment of social distancing measures in the United States during the early course of the COVID-19 pandemic. Their correlation and earlier rise and peak in correlative strength with R_t when compared to social mobility may provide proactive insight into whether social distancing efforts are sufficiently enacted. Whether these findings translate to the hypothesized clinical value is uncertain due to limitations. Although social media remains a candidate to gauge the success of this containment measure in the early epidemic period, future studies should investigate how social media reactions change during the course of the epidemic and whether these correlation patterns with R_t persist.

Conflicts of Interest

None declared.

References

1. Pan A, Liu L, Wang C, Guo H, Hao X, Wang Q, et al. Association of public health interventions with the epidemiology of the COVID-19 outbreak in Wuhan, China. *JAMA* 2020 May 19;323(19):1915-1923 [FREE Full text] [doi: [10.1001/jama.2020.6130](https://doi.org/10.1001/jama.2020.6130)] [Medline: [32275295](https://pubmed.ncbi.nlm.nih.gov/32275295/)]
2. Liu Y, Gayle AA, Wilder-Smith A, Rocklöv J. The reproductive number of COVID-19 is higher compared to SARS coronavirus. *J Travel Med* 2020 Mar 13;27(2) [FREE Full text] [doi: [10.1093/jtm/taaa021](https://doi.org/10.1093/jtm/taaa021)] [Medline: [32052846](https://pubmed.ncbi.nlm.nih.gov/32052846/)]
3. Delen D, Eryarsoy E, Davazdahemami B. No place like home: cross-national data analysis of the efficacy of social distancing during the COVID-19 pandemic. *JMIR Public Health Surveill* 2020 May 28;6(2):e19862 [FREE Full text] [doi: [10.2196/19862](https://doi.org/10.2196/19862)] [Medline: [32434145](https://pubmed.ncbi.nlm.nih.gov/32434145/)]
4. Athreya KB, Mather R, Mustre-del-Río J, Sanchez JM. COVID-19 and households' financial distress: part 2: the spread of COVID-19 and (financial) pre-existing conditions. Federal Reserve Bank of Richmond. 2020 Mar 30. URL: <https://www.richmondfed.org/publications/research/> [accessed 2020-04-05]
5. CDC COVID-19 Response Team. Geographic differences in COVID-19 cases, deaths, and incidence - United States, February 12-April 7, 2020. *MMWR Morb Mortal Wkly Rep* 2020 Apr 17;69(15):465-471. [doi: [10.15585/mmwr.mm6915e4](https://doi.org/10.15585/mmwr.mm6915e4)] [Medline: [32298250](https://pubmed.ncbi.nlm.nih.gov/32298250/)]
6. Lee JC, Mervosh S, Avila Y, Harvey B, Matthews AL, Gamio L, et al. See how all 50 states are reopening (and closing again). *The New York Times*. 2020 Jun. URL: <https://www.nytimes.com/interactive/2020/us/states-reopen-map-coronavirus.html> [accessed 2020-08-01]
7. Culter D. How will COVID-19 affect the health care economy? *JAMA Network*. 2020 Apr 09. URL: <https://jamanetwork.com/channels/health-forum/fullarticle/2764547> [accessed 2020-04-27]
8. H.R.74 - Grant's Law 116th Congress (2019-2020). Library of Congress. 2020 Jan 03. URL: <https://www.congress.gov/bill/116th-congress/house-bill/74>
9. Walensky RP, Del Rio C. From mitigation to containment of the COVID-19 pandemic: putting the SARS-CoV-2 genie back in the bottle. *JAMA* 2020 May 19;323(19):1889-1890. [doi: [10.1001/jama.2020.6572](https://doi.org/10.1001/jama.2020.6572)] [Medline: [32301959](https://pubmed.ncbi.nlm.nih.gov/32301959/)]
10. Mobility trends reports. Apple. URL: <https://www.apple.com/covid19/mobility> [accessed 2020-04-15]
11. COVID-19 community mobility reports. Google. URL: <https://www.google.com/covid19/mobility> [accessed 2020-04-15]
12. Park JH, Christman MP, Linos E, Rieder EA. Dermatology on Instagram: an analysis of hashtags. *J Drugs Dermatol* 2018 Apr 01;17(4):482-484 [FREE Full text] [Medline: [29601627](https://pubmed.ncbi.nlm.nih.gov/29601627/)]
13. Dorfman R, Vaca E, Mahmood E, Fine N, Schierle C. Plastic surgery-related hashtag utilization on Instagram: implications for education and marketing. *Aesthet Surg J* 2018 Feb 15;38(3):332-338. [doi: [10.1093/asj/sjx120](https://doi.org/10.1093/asj/sjx120)] [Medline: [29040378](https://pubmed.ncbi.nlm.nih.gov/29040378/)]
14. Sinnenberg L, Bottenheim AM, Padrez K, Mancheno C, Ungar L, Merchant RM. Twitter as a tool for health research: a systematic review. *Am J Public Health* 2017 Jan;107(1):e1-e8. [doi: [10.2105/AJPH.2016.303512](https://doi.org/10.2105/AJPH.2016.303512)] [Medline: [27854532](https://pubmed.ncbi.nlm.nih.gov/27854532/)]
15. Bloom R, Amber KT, Hu S, Kirsner R. Google search trends and skin cancer: evaluating the US population's interest in skin cancer and its association with melanoma outcomes. *JAMA Dermatol* 2015 Aug;151(8):903-905. [doi: [10.1001/jamadermatol.2015.1216](https://doi.org/10.1001/jamadermatol.2015.1216)] [Medline: [26061357](https://pubmed.ncbi.nlm.nih.gov/26061357/)]
16. Solano P, Ustulin M, Pizzorno E, Vichi M, Pompili M, Serafini G, et al. A Google-based approach for monitoring suicide risk. *Psychiatry Res* 2016 Dec 30;246:581-586. [doi: [10.1016/j.psychres.2016.10.030](https://doi.org/10.1016/j.psychres.2016.10.030)] [Medline: [27837725](https://pubmed.ncbi.nlm.nih.gov/27837725/)]

17. Moccia M, Palladino R, Falco A, Saccà F, Lanzillo R, Brescia Morra V. Google Trends: new evidence for seasonality of multiple sclerosis. *J Neurol Neurosurg Psychiatry* 2016 Sep;87(9):1028-1029. [doi: [10.1136/jnnp-2016-313260](https://doi.org/10.1136/jnnp-2016-313260)] [Medline: [27083532](https://pubmed.ncbi.nlm.nih.gov/27083532/)]
18. Lu Y, Zhang L. Social media WeChat infers the development trend of COVID-19. *J Infect* 2020 Jul;81(1):e82-e83 [FREE Full text] [doi: [10.1016/j.jinf.2020.03.050](https://doi.org/10.1016/j.jinf.2020.03.050)] [Medline: [32283142](https://pubmed.ncbi.nlm.nih.gov/32283142/)]
19. Wojcik S, Hughes A. Sizing up Twitter users. Pew Research Center. 2019 Apr 24. URL: <https://www.pewresearch.org/internet/2019/04/24/sizing-up-twitter-users/> [accessed 2020-04-12]
20. Clement J. Percentage of U.S. adults who use Instagram as of February 2019, by age group. Statista. 2019 Aug. URL: <https://www.statista.com/statistics/246199/share-of-us-internet-users-who-use-instagram-by-age-group/> [accessed 2020-04-15]
21. Simonsen L, Gog JR, Olson D, Viboud C. Infectious disease surveillance in the big data era: towards faster and locally relevant systems. *J Infect Dis* 2016 Dec 01;214(suppl_4):S380-S385 [FREE Full text] [doi: [10.1093/infdis/jiw376](https://doi.org/10.1093/infdis/jiw376)] [Medline: [28830112](https://pubmed.ncbi.nlm.nih.gov/28830112/)]
22. Merchant RM, Lurie N. Social media and emergency preparedness in response to novel coronavirus. *JAMA* 2020 May 26;323(20):2011-2012. [doi: [10.1001/jama.2020.4469](https://doi.org/10.1001/jama.2020.4469)] [Medline: [32202611](https://pubmed.ncbi.nlm.nih.gov/32202611/)]
23. Al-Dmour H, Masa'deh R, Salman A, Abuhashesh M, Al-Dmour R. Influence of social media platforms on public health protection against the COVID-19 pandemic via the mediating effects of public health awareness and behavioral changes: integrated model. *J Med Internet Res* 2020 Aug 19;22(8):e19996 [FREE Full text] [doi: [10.2196/19996](https://doi.org/10.2196/19996)] [Medline: [32750004](https://pubmed.ncbi.nlm.nih.gov/32750004/)]
24. Previous U.S. COVID-19 case data. Centers for Disease Control and Prevention. 2020. URL: <https://www.cdc.gov/coronavirus/2019-ncov/cases-updates/previouscases.html> [accessed 2020-04-22]
25. Gardner L. Public health: mapping COVID-19. Johns Hopkins Center for Systems Science and Engineering. 2020 Jan 23. URL: <https://systems.jhu.edu/research/public-health/ncov/> [accessed 2020-04-26]
26. Clement J. Worldwide desktop market share of leading search engines from January 2010 to July 2020. Statista. 2020. URL: <https://www.statista.com/statistics/216573/worldwide-market-share-of-search-engines/> [accessed 2020-04-15]
27. Unamo. URL: <https://unamo.com/> [accessed 2020-04-15]
28. Fox S, Rainie L. The web at 25 in the U.S. Pew Research Center. 2014 Feb 27. URL: <http://www.pewinternet.org/2014/02/27/the-web-at-25-in-the-u-s/> [accessed 2020-04-12]
29. Stepleton K. Unemployment insurance weekly claims. US Department of Labor. 2020 Oct 08. URL: <https://www.dol.gov/ui/data.pdf> [accessed 2020-04-28]
30. Du Z, Xu X, Wu Y, Wang L, Cowling BJ, Meyers LA. Serial interval of COVID-19 among publicly reported confirmed cases. *Emerg Infect Dis* 2020 Jun;26(6):1341-1343. [doi: [10.3201/eid2606.200357](https://doi.org/10.3201/eid2606.200357)] [Medline: [32191173](https://pubmed.ncbi.nlm.nih.gov/32191173/)]
31. Lauer SA, Grantz KH, Bi Q, Jones FK, Zheng Q, Meredith HR, et al. The incubation period of coronavirus disease 2019 (COVID-19) from publicly reported confirmed cases: estimation and application. *Ann Intern Med* 2020 May 05;172(9):577-582. [doi: [10.7326/m20-0504](https://doi.org/10.7326/m20-0504)]

Abbreviations

R_t: time-varying reproduction number

R₀: basic reproductive number

SVI: search volume index

Edited by T Sanchez; submitted 11.06.20; peer-reviewed by L Sinnenberg, K Bosh, C Campos-Castillo; comments to author 23.07.20; revised version received 20.08.20; accepted 16.09.20; published 20.10.20.

Please cite as:

Younis J, Freitag H, Ruthberg JS, Romanes JP, Nielsen C, Mehta N

Social Media as an Early Proxy for Social Distancing Indicated by the COVID-19 Reproduction Number: Observational Study

JMIR Public Health Surveill 2020;6(4):e21340

URL: <http://publichealth.jmir.org/2020/4/e21340/>

doi:[10.2196/21340](https://doi.org/10.2196/21340)

PMID:[33001831](https://pubmed.ncbi.nlm.nih.gov/33001831/)

©Joseph Younis, Harvy Freitag, Jeremy S Ruthberg, Jonathan P Romanes, Craig Nielsen, Neil Mehta. Originally published in *JMIR Public Health and Surveillance* (<http://publichealth.jmir.org>), 20.10.2020. This is an open-access article distributed under the terms of the Creative Commons Attribution License (<https://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in *JMIR Public Health and Surveillance*, is properly cited. The complete bibliographic information, a link to the original publication on <http://publichealth.jmir.org>, as well as this copyright and license information must be included.

Original Paper

Online Public Attention During the Early Days of the COVID-19 Pandemic: Infoveillance Study Based on Baidu Index

Xue Gong^{1*}, BS; Yangyang Han^{1*}, BS; Mengchi Hou¹, BS; Rui Guo¹, PhD

School of Public Health, Capital Medical University, Beijing, China

*these authors contributed equally

Corresponding Author:

Rui Guo, PhD

School of Public Health

Capital Medical University

No 10 Youanmenwai, Xitoutiao

Beijing

China

Phone: 86 01083911573

Email: guorui@ccmu.edu.cn

Abstract

Background: The COVID-19 pandemic has become a global public health event, attracting worldwide attention. As a tool to monitor public awareness, internet search engines have been widely used in public health emergencies.

Objective: This study aims to use online search data (Baidu Index) to monitor the public's attention and verify internet search engines' function in public attention monitoring of public health emergencies.

Methods: We collected the Baidu Index and the case monitoring data from January 20, 2020, to April 20, 2020. We combined the Baidu Index of keywords related to COVID-19 to describe the public attention's temporal trend and spatial distribution, and conducted the time lag cross-correlation analysis.

Results: The Baidu Index temporal trend indicated that the changes of the Baidu Index had a clear correspondence with the development time node of the pandemic. The Baidu Index spatial distribution showed that in the regions of central and eastern China, with denser populations, larger internet user bases, and higher economic development levels, the public was more concerned about COVID-19. In addition, the Baidu Index was significantly correlated with six case indicators of new confirmed cases, new death cases, new cured discharge cases, cumulative confirmed cases, cumulative death cases, and cumulative cured discharge cases. Moreover, the Baidu Index was 0-4 days earlier than new confirmed and new death cases, and about 20 days earlier than new cured and discharged cases while 3-5 days later than the change of cumulative cases.

Conclusions: The national public's demand for epidemic information is urgent regardless of whether it is located in the hardest hit area. The public was more sensitive to the daily new case data that represents the progress of the epidemic, but the public's attention to the epidemic situation in other areas may lag behind. We could set the Baidu Index as the sentinel and the database in the online infoveillance system for infectious disease and public health emergencies. According to the monitoring data, the government needs to prevent and control the possible outbreak in advance and communicate the risks to the public so as to ensure the physical and psychological health of the public in the epidemic.

(*JMIR Public Health Surveill* 2020;6(4):e23098) doi:[10.2196/23098](https://doi.org/10.2196/23098)

KEYWORDS

Baidu Index; public attention; time lag cross-correlation analysis; COVID-19

Introduction

As a Public Health Emergency of International Concern [1], the COVID-19 pandemic swept 215 countries and regions with high transmission speed, wide infection range, and difficulty in prevention and control [2,3]. As of July 21, 2020, the number

of cumulative confirmed cases worldwide exceeded 14.7 million, and the number of cumulative death cases exceeded 600,000 [3]. COVID-19 has caused challenges and threats to public health in China and the world, attracting widespread public attention.

Existing online search data is a voluntary expression of the public, reflecting public attention and needs; compared with the traditional survey data, it has greater timeliness, objectivity, and credibility [4-7]. Search engines, as the representative of internet-based sources, have been proven to detect the initial evidence of an epidemic [8]. Internet-based technology provides essential benefits for improving the transparency of epidemic reporting and complementing the traditional surveillance, enabling health institutions to respond quickly in a targeted manner, thereby reducing morbidity, mortality, and disease outbreaks [8-11]. Many studies have shown that the internet search engine, as a monitoring platform for public concern in public health emergencies, has become an “outpost” for early warning of the epidemic. On the one hand, the internet search data correlated with traditional reported data (such as laboratory confirmed data and death data) [12,13]. On the other hand, internet search data tended to be ahead of case data. For example, Polgreen et al [14] used the Yahoo search engine to collect influenza data and found that it was 1-3 weeks and 5 weeks earlier than the routine reporting of laboratory confirmed cases and influenza deaths, respectively; Ginsberg et al [15] proposed the concept of Google Flu Trends in 2009 and found that Google predicted results were 1-2 weeks earlier than the Centers for Disease Control and Prevention flu surveillance system report in the United States. For COVID-19, Li et al [16] found that the internet search data from Google Trends, Baidu Index (BDI), and Sina Weibo Index was 8-10 days earlier for new laboratory-confirmed cases and 5-7 days earlier for new suspected cases [16]. Therefore, it is an important reference for social demand monitoring. In China, Baidu search’s penetration rate reached 90.9% among internet search engine users as of October 2019, equivalent to Google’s role in western countries [17]. At present, scholars have used Google and Baidu search to obtain internet data. Their applicability in monitoring public attention of public health emergencies such as influenza [15-18], H7N9 [19,20], and Dengue [21,22] has been widely confirmed.

To date, none of the studies combine temporal and spatial relationship, and relevance between search engines and public attention under the COVID-19 pandemic and focus on the differences in public concerns between hardest hit and non-hardest-hit areas. Thus, this study aims to use BDI to monitor the public’s attention and verify internet search engines’ function in public attention monitoring of public health emergencies.

Methods

Real-World Databases

We selected six case indicators for real-world data, including *new confirmed cases*, *new death cases*, *new cured discharge cases*, *cumulative confirmed cases*, *cumulative death cases*, and *cumulative cured discharge cases* (Multimedia Appendix 1). We collected real-world data from January 20, 2020, to April 20, 2020. The National Health Commission of the People’s

Republic of China has compiled and released the number of cases in each province daily from January 20, 2020. Considering the data reliability, we used the official data reported by the government, so we selected January 20 as the start time of the study. The reason for choosing April 20, 2020, as the deadline is that Hubei Province, the hardest hit area, reported only three new confirmed cases in the past month. Medical teams from other provinces had been withdrawn one after another from Hubei Province. The national economic and social order is gradually recovering. It can be considered that the COVID-19 epidemic in China had entered the normalization stage. Real-world data comes from the daily outbreak notification of the official website of the National Health Commission of the People’s Republic of China [23].

BDI Databases

In the early stage of the epidemic, there was no unified name for COVID-19. Taking into account the BDI algorithm, a common expression of the Chinese public, and scholars’ research on the main topics discussed by netizens during the epidemic [22], we selected “Novel coronavirus (新型冠状病毒),” “Pneumonia (肺炎),” “New pneumonia (新型肺炎),” “Novel Coronavirus Pneumonia (新型冠状病毒肺炎),” “Epidemic (疫情),” “Wuhan (武汉),” and “Wuhan Pneumonia (武汉肺炎),” seven Chinese words with large data values as the BDI-related keywords. These keywords include pneumonia, Wuhan, virus, and other words that can represent epidemic events. The combined BDI of seven keywords was used as the BDI data for COVID-19. We collected BDI data from December 8, 2019, to April 20, 2020, which is different from the real-world data collection time because BDI was already high on January 20, 2020. To more fully demonstrate the changes in public attention in the early stage of the epidemic, the start time of BDI data collection was advanced to the onset of the first confirmed COVID-19 case notified by the Wuhan Municipal Health Commission. BDI data comes from the BDI official website [24].

Analysis

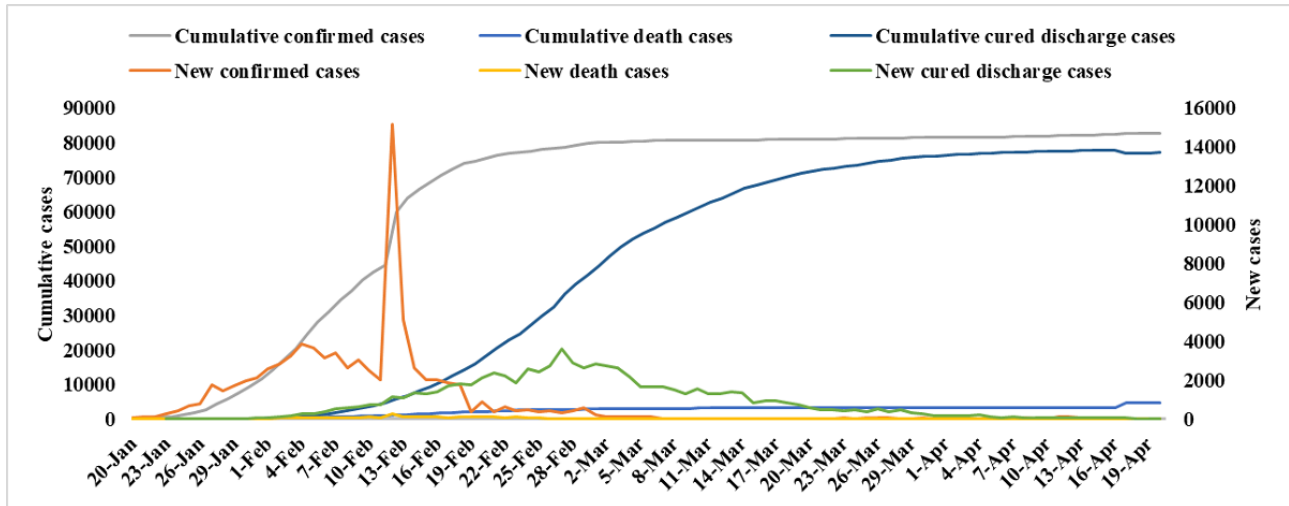
We used Excel 2019 (Microsoft Corporation) for database construction. The curve of COVID-19 case-related indicators and BDI was plotted to describe the development trend of the epidemic and the changing trend of public attention. Time lag cross-correlation analysis of BDI and case data was performed using SPSS 26.0 English version (IBM Corp) to explore the correlation between public concern and the actual epidemic. Considering the data comparability, the correlation analysis time was from January 20, 2020, to April 20, 2020.

Results

COVID-19 Epidemic Trend

We used six case indicators from real-world data to depict the characteristics of the COVID-19 outbreak in China between January 20, 2020, and April 20, 2020 (Figure 1).

Figure 1. The epidemic characteristics of COVID-19 in China from January 20 to April 20, 2020.

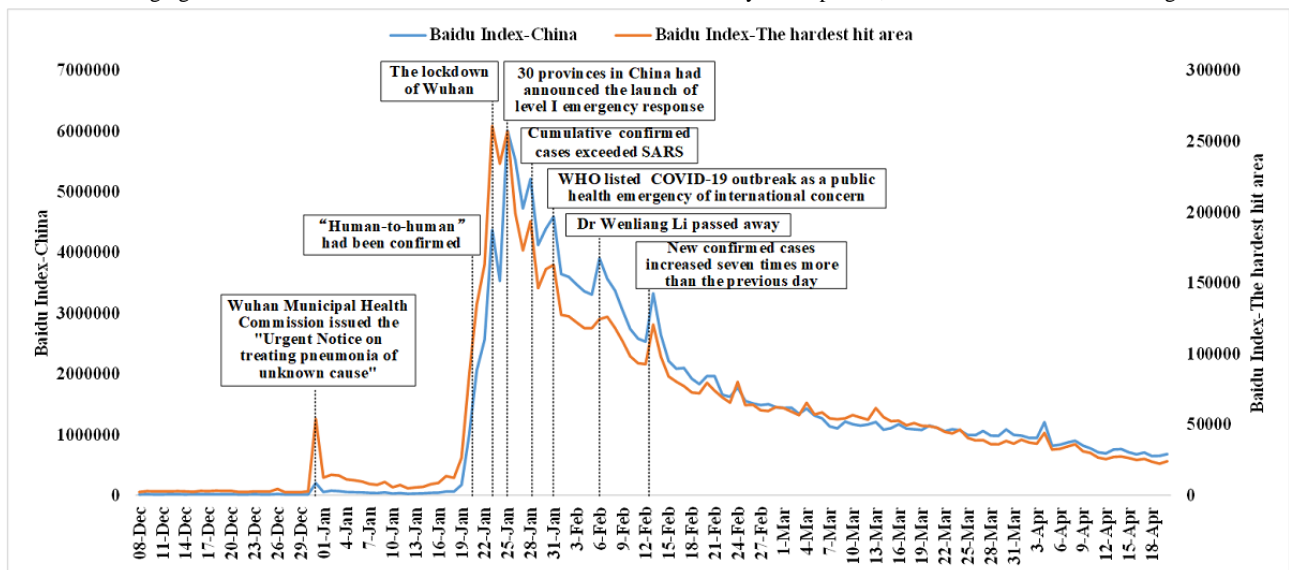


BDI Temporal Trend

During December 8, 2019, to April 20, 2020, the trend of the COVID-19 BDI in China experienced a state of “developing from nothing, reaching a peak, fulling volatility, and stabilizing gradually” (Figure 2). At the beginning of the observation period, the BDI was at an extremely low level. The first small peak appeared on December 31, 2019. The BDI increased significantly from January 20, with a small peak on January 23,

and the BDI reached its peak on January 25. Subsequently, the BDI fluctuated and declined, during which there were several small peaks on January 28, January 31, February 6, and February 13. After February 13, the BDI declined steadily with the decrease of new confirmed cases and the increase of new cured and discharged cases. By the end of observation (April 20, 2020), the BDI was still significantly higher than the level at the beginning of observation (December 8, 2019).

Figure 2. The changing trend of the Baidu Index of COVID-19 in China from January 2 to April 20, 2020. WHO: World Health Organization.



BDI Spatial Distribution

Figure 3 and Table 1 show the daily average BDI and per capita BDI of all provinces in China from December 8, 2019, to April 20, 2020. The BDI was significantly concentrated in the central and eastern regions of China. The daily average BDI in Guangdong, Shandong, Jiangsu, Beijing, Hebei, Zhejiang,

Sichuan, Henan, Hubei, and Liaoning exceeded 50,000 in search frequency. Taking into account the different population densities and internet user bases in different provinces, we calculated the per capita BDI of each province through internet users (per capita BDI = daily average BDI / internet users). The top ten provinces were Beijing, Tianjin, Shanghai, Liaoning, Hubei, Jilin, Shandong, Hebei, Heilongjiang, and Jiangsu.

Figure 3. The spatial distribution of daily average Baidu Index from December 8, 2019, to April 20, 2020.



Table 1. The daily average BDI and per capita BDI in each province from December 8, 2019, to April 20, 2020.

Provinces	Daily average BDI ^a	Internet users × 10,000	Per capita BDI/10,000
Guangdong	127,511	14,106.9	9.04
Shandong	96,490	8418.6	11.46
Jiangsu	89,553	7979.5	11.22
Beijing	74,987	3291.1	22.78
Hebei	74,383	6505.3	11.43
Zhejiang	73,434	6833.6	10.75
Sichuan	69,057	7332.0	9.42
Henan	67,697	7766.5	8.72
Hubei	53,996	4552.0	11.86
Liaoning	51,363	3905.9	13.15
Shanghai	49,003	3032.0	16.16
Anhui	47,715	4596.3	10.38
Hunan	44,501	5226.6	8.51
Fujian	36,810	3793.6	9.70
Jiangxi	33,595	3340.8	10.06
Shanxi	33,011	3726.8	8.86
Heilongjiang	33,000	2894.9	11.40
Shanxi	32,243	3086.3	10.45
Chongqing	28,544	2862.2	9.97
Jilin	27,191	2366.2	11.49
Guangxi	26,405	4130.8	6.39
Yunnan	24,577	3918.9	6.27
Tianjin	23,079	1352.5	17.06
Neimenggu	22,845	2508.1	9.11
Guizhou	21,656	3323.1	6.52
Gansu	17,628	2210.6	7.97
Xinjiang	14,231	1992.5	7.14
Hainan	9759	914.0	10.68
Ningxia	6015	694.6	8.66
Qinghai	5453	559.0	9.75
Xizang	2409	260.2	9.26

^aBDI: Baidu Index.

Time Lag Cross-Correlation Analysis

Correlation Analysis of BDI and Real-World Data in China

We conducted the time lag cross-correlation analysis between national BDI and six case indicators to explore key case indicators that may cause public attention fluctuations and the relationship between the BDI and case indicators. The results showed that, except for new cured and discharged cases, the other five case indicators were significantly correlated with BDI within the time range of 6 days earlier or lagging (Table 2). The

correlation between the BDI and new confirmed cases was the highest at a lag of 0 days (Spearman correlation coefficient 0.795). The correlation with new death cases was highest at a lag of -4 days (Spearman correlation coefficient 0.876). The correlation between the BDI and cumulative confirmed cases, cumulative death cases, and cumulative cured and discharged cases reached the highest level at a lag of 5 days, 4 days, and 3 days, respectively (Spearman correlation coefficients were 0.989, 0.983, and 0.947, respectively). That is, the public attention to the epidemic was 4 days earlier than the change of new death cases and 3-5 days later than the change of cumulative cases.

Table 2. The correlation between the national COVID-19 Baidu Index and real-world data from January 20 to April 20, 2020.

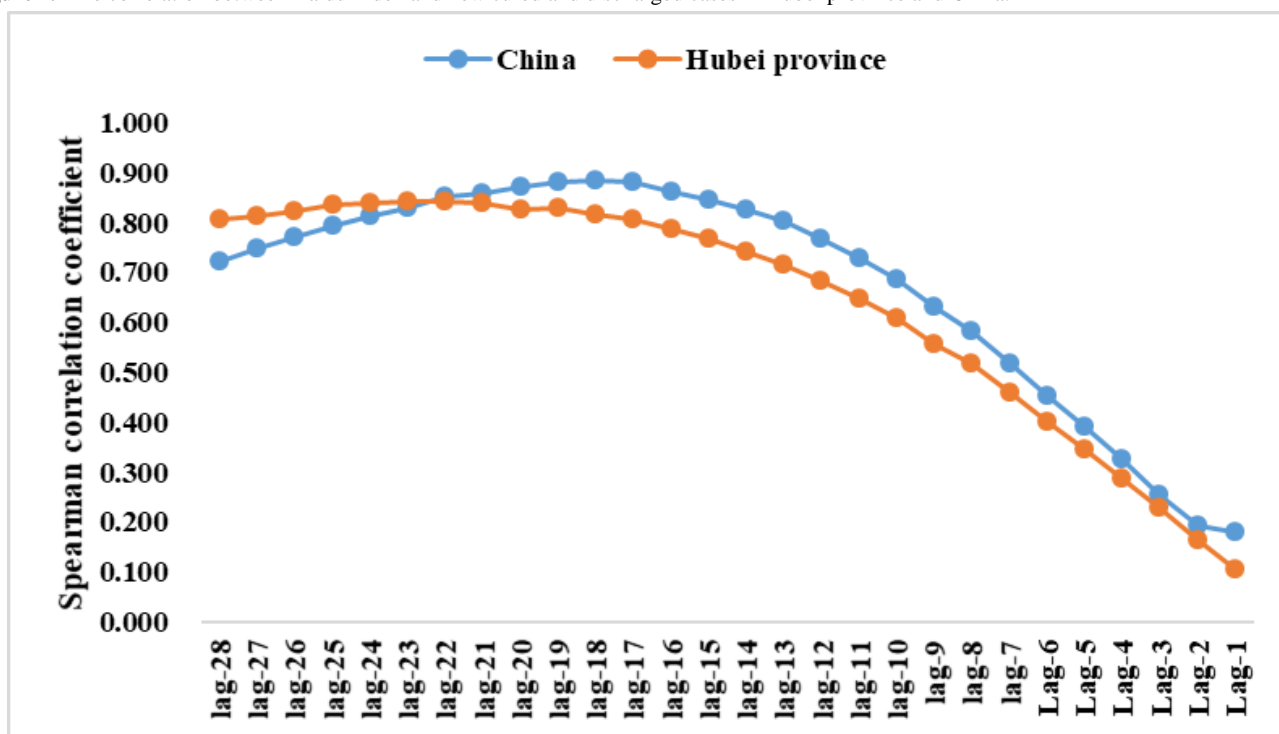
Baidu Index	New confirmed cases	New death cases	New cured discharge cases	Cumulative confirmed cases	Cumulative death cases	Cumulative cured discharge cases
Lag -6 days						
Spearman correlation coefficient	0.689	0.868	0.452	-0.576	-0.583	-0.678
<i>P</i> value	<.001	<.001	<.001	<.001	<.001	<.001
Lag -5 days						
Spearman correlation coefficient	0.721	0.873	0.391	-0.633	-0.639	-0.729
<i>P</i> value	<.001	<.001	<.001	<.001	<.001	<.001
Lag -4 days						
Spearman correlation coefficient	0.751	0.876	0.325	-0.692	-0.695	-0.793
<i>P</i> value	<.001	<.001	.002	<.001	<.001	<.001
Lag -3 days						
Spearman correlation coefficient	0.775	0.865	0.255	-0.753	-0.754	-0.846
<i>P</i> value	<.001	<.001	.02	<.001	<.001	<.001
Lag -2 days						
Spearman correlation coefficient	0.776	0.855	0.193	-0.814	-0.814	-0.905
<i>P</i> value	<.001	<.001	.07	<.001	<.001	<.001
Lag -1 day						
Spearman correlation coefficient	0.789	0.841	0.180	-0.878	-0.875	-0.933
<i>P</i> value	<.001	<.001	.09	<.001	<.001	<.001
Lag 0						
Spearman correlation coefficient	0.795	0.806	0.170	-0.942	-0.941	-0.942
<i>P</i> value	<.001	<.001	.11	<.001	<.001	<.001
Lag 1 day						
Spearman correlation coefficient	0.780	0.769	0.165	-0.977	-0.974	-0.941
<i>P</i> value	<.001	<.001	.12	<.001	<.001	<.001
Lag 2 days						
Spearman correlation coefficient	0.772	0.748	0.165	-0.983	-0.978	-0.942
<i>P</i> value	<.001	<.001	.12	<.001	<.001	<.001
Lag 3 days						
Spearman correlation coefficient	0.759	0.738	0.165	-0.987	-0.982	-0.947
<i>P</i> value	<.001	<.001	.12	<.001	<.001	<.001
Lag 4 days						
Spearman correlation coefficient	0.759	0.733	0.162	-0.988	-0.983	-0.945
<i>P</i> value	<.001	<.001	.13	<.001	<.001	<.001
Lag 5 days						

Baidu Index	New confirmed cases	New death cases	New cured discharge cases	Cumulative confirmed cases	Cumulative death cases	Cumulative cured discharge cases
Spearman correlation coefficient	0.763	0.723	0.163	-0.989	-0.983	-0.944
P value	<.001	<.001	.13	<.001	<.001	<.001
Lag 6 days						
Spearman correlation coefficient	0.754	0.729	0.164	-0.989	-0.983	-0.943
P value	<.001	<.001	.13	<.001	<.001	<.001

To further explore the relationship between the BDI and new cured and discharged cases, we analyzed the correlation between the two within the 4 weeks lagging. The results showed that the correlation between the BDI and new cured and discharged cases was the highest at a lag of -18 days (Spearman correlation

coefficient 0.883). That is, public attention to the epidemic was 18 days earlier than the change of new cured and discharged cases. The change of the Spearman correlation coefficient is shown in Figure 4.

Figure 4. The correlation between Baidu Index and new cured and discharged cases in Hubei province and China.



Correlation Analysis of BDI and Real-World Data in Hubei Province

To understand whether the public attention to the epidemic in Hubei Province, the hardest hit area, is different from that of the whole country, we conducted the time lag cross-correlation analysis between the BDI and six case indicators of Hubei Province. The results were consistent with the correlation analysis of the national BDI and case data (Table 3). The correlation between the BDI and new confirmed cases was the highest at a lag of -1 day (Spearman correlation coefficient

0.870), and the correlation with new death cases was highest at a lag of -4 days (Spearman correlation coefficient 0.853). The correlation between BDI and cumulative confirmed cases, cumulative death cases, and cumulative cured and discharged cases reached the highest level at a lag of 2 days, 2 days, and 3 days, respectively (Spearman correlation coefficients were 0.992, 0.993, and 0.985, respectively). That is, the public attention to the epidemic was 1 day and 4 days earlier than the change of new confirmed cases and new death cases, and 3-5 days later than the change of three cumulative cases.

Table 3. The correlation between COVID-19 Baidu Index and real-world data from January 20 to April 20, 2020, in Hubei Province.

Baidu Index in hardest hit area	New confirmed cases	New death cases	New cured discharge cases	Cumulative confirmed cases	Cumulative death cases	Cumulative cured discharge cases
Lag -6 days						
Spearman correlation coefficient	0.819	0.852	0.401	-0.620	-0.622	-0.613
<i>P</i> value	<.001	<.001	<.001	<.001	<.001	<.001
Lag -5 days						
Spearman correlation coefficient	0.839	0.850	0.346	-0.678	-0.681	-0.672
<i>P</i> value	<.001	<.001	<.001	<.001	<.001	<.001
Lag -4 days						
Spearman correlation coefficient	0.858	0.853	0.287	-0.737	-0.741	-0.733
<i>P</i> value	<.001	<.001	.006	<.001	<.001	<.001
Lag -3 days						
Spearman correlation coefficient	0.862	0.837	0.228	-0.799	-0.803	-0.794
<i>P</i> value	<.001	<.001	.03	<.001	<.001	<.001
Lag -2 days						
Spearman correlation coefficient	0.866	0.824	0.164	-0.862	-0.866	-0.857
<i>P</i> value	<.001	<.001	.12	<.001	<.001	<.001
Lag -1 day						
Spearman correlation coefficient	0.870	0.796	0.106	-0.927	-0.931	-0.920
<i>P</i> value	<.001	<.001	.31	<.001	<.001	<.001
Lag 0 days						
Spearman correlation coefficient	0.868	0.755	0.046	-0.984	-0.987	-0.978
<i>P</i> value	<.001	<.001	.67	<.001	<.001	<.001
Lag 1 days						
Spearman correlation coefficient	0.862	0.740	0.032	-0.989	-0.992	-0.983
<i>P</i> value	<.001	<.001	.76	<.001	<.001	<.001
Lag 2 days						
Spearman correlation coefficient	0.852	0.730	0.031	-0.992	-0.993	-0.984
<i>P</i> value	<.001	<.001	.77	<.001	<.001	<.001
Lag 3 days						
Spearman correlation coefficient	0.850	0.731	0.034	-0.991	-0.993	-0.985
<i>P</i> value	<.001	<.001	.75	<.001	<.001	<.001
Lag 4 days						
Spearman correlation coefficient	0.858	0.729	0.032	-0.991	-0.993	-0.985
<i>P</i> value	<.001	<.001	.76	<.001	<.001	<.001
Lag 5 days						

Baidu Index in hardest hit area	New confirmed cases	New death cases	New cured discharge cases	Cumulative confirmed cases	Cumulative death cases	Cumulative cured discharge cases
Spearman correlation coefficient	0.850	0.726	0.032	-0.992	-0.993	-0.984
<i>P</i> value	<.001	<.001	.76	<.001	<.001	<.001
Lag 6 days						
Spearman correlation coefficient	0.851	0.731	0.036	-0.992	-0.993	-0.984
<i>P</i> value	<.001	<.001	.73	<.001	<.001	<.001

To further explore the relationship between the BDI and new cured and discharged cases in Hubei Province, we analyzed the correlation between the two within the time range of 4 weeks lagging. The results showed that the correlation between the BDI and new cured and discharged cases in Hubei Province was the highest at a lag of -22 days (Spearman correlation coefficient 0.844). That is, public attention to the epidemic was 22 days earlier than the change of new cured and discharged cases. The change of the Spearman correlation coefficient is shown in [Figure 4](#).

Discussion

Principal Finding

The BDI can well fit the development of the COVID-19 epidemic in time and space, and we found that there were significant advance and delay effects between the BDI and the real-world case data. In brief, internet search data can be used for monitoring and early warning of public health emergencies, including the BDI used in this study and Google Trends used in other related studies. Thus, it can be said that internet search data supplements the government statistics official data lag [8].

The Space-Time Distribution of the BDI Showed the Progress of the Epidemic

The BDI temporal trend showed that the changes in the BDI corresponded to COVID-19 news and major events, similar to other studies [25]. On December 30, 2019, Wuhan Municipal Health Commission issued the "Urgent Notice on treating pneumonia of unknown cause." On this day, the expert team of the National Health Commission of the People's Republic of China arrived in Wuhan to formally intervene in the investigation, which was the reason for the first small wave of the BDI. On January 20, 2020, expert Zhong Nanshan clarified the characteristics of COVID-19 person-to-person transmission. Simultaneously, the State Council incorporated COVID-19 into the Infectious Disease Law, which aroused wide public concern, and the BDI increased significantly. The BDI reached another small peak on January 23, probably due to the public panic caused by Wuhan's lockdown on that day. On January 25, the BDI peaked as 30 provinces in China had announced the launch of a level I emergency response to public health emergencies. Subsequently, the BDI declined with fluctuation and several small peaks. The epidemic development events leading to the BDI fluctuations are marked in [Figure 2](#).

Although internet search engines are reliable tools for epidemic infoveillance, information disseminated through the news media

may affect search volumes and have an event amplification effect [26,27], thus increasing people's attention to the epidemic. In this study, major events marked in [Figure 2](#), which may lead to the BDI peak or small peak, had been widely reported by various social media. The reports quickly ignited the public's attention to the epidemic, which led to an increase in BDI searches. In the early stage of the epidemic, the public knew little about the epidemic, and the information on social media was relatively fragmented. Besides, the epidemic was unstable and highly contagious, so the public actively searched for information to learn more about the epidemic. With the development of the epidemic and the accumulation of historical information, real-time dynamic information that can reflect the epidemic is also embedded in netizens' social software. Users can directly read and obtain the information without an active search. Therefore, the public is more accustomed to passively accepting information, reducing its search behavior for epidemics [28].

The spatial distribution of the daily average BDI showed that the public attention to COVID-19 was concentrated in areas with denser populations, larger internet user bases, and higher economic development levels. In addition, there was a significant difference between the east and the west, with coastal provinces paying more attention to the epidemic than inland provinces. This finding was consistent with the research results of Han et al [25] and Sun et al [28]. As the epicenter of the COVID-19 outbreak, Wuhan, Hubei is undoubtedly a hot spot of public concern [25]. Most other regions such as the Beijing-Tianjin-Hebei and Guangdong, Jiangsu, Shandong, Zhejiang, and other coastal areas have denser populations, larger internet user bases, and higher economic development levels. In 2018, the top 10 provinces with daily average BDI accounted for 52.4%, 57.4%, and 59.1% of the 31 provinces in the country in terms of year-end population, GDP, and internet users, respectively [29]. In addition, the high levels of economic development and population density mean that these areas have convenient transportation infrastructure and network communications. These factors may increase the possibility of a faster epidemic spread and panic among the population, making it more challenging to prevent and control the epidemic. At the same time, we should also pay attention to areas with low internet search volume, as their information depends on passive access rather than active access. The government and other official propaganda media should broaden their channels so that people can obtain positive and effective information, and information fairness can be realized.

BDI Has Significant Temporal Difference With Real-World Data

The time lag cross-correlation analysis showed a significant correlation between the BDI and the six case indicators regardless of the hardest hit area or other areas. In addition, the BDI had an advance effect compared to new cases and a lag effect compared to cumulative cases, indicating that the public was more sensitive to new cases. New cases can represent the severity of the epidemic. The public usually judges the current or future trend of the epidemic based on new cases. For confirmed, death, and cured and discharged cases, the cumulative cases are simply a superposition of new cases, representing the epidemic's situation over a period of time.

In addition, in the correlation analysis between the BDI and new cases, the BDI was 0-4 days earlier than new confirmed and new death cases, and about 20 days earlier than new cured and discharged cases. In fact, "suspected- confirmed- treated-cured" is a phased development process with time sequence [28]. In the early stage of the outbreak, confirmed cases kept increasing, while the substantial increase in cured and discharged cases was later. Compared to new cases, the advance effect may represent a reporting bias rooted in testing delays [27]. COVID-19 is a newly discovered disease that requires laboratory testing for diagnosis. There is a time interval between the appearance of disease symptoms and the final diagnosis. The reporting bias further demonstrates the importance of real-time disease development assessment [16].

In addition, the BDI positively correlated with new cases but negatively correlated with cumulative cases. The positive correlation reflected the public's panic about the epidemic. The public had little knowledge about the virus, so they paid particular attention to the daily new case data representing the epidemic's progress. The negative correlation reflected the positive attitude of the Chinese public to the epidemic. With the continuous strengthening of epidemic prevention and control, the increase in cumulative confirmed cases and cumulative death cases had slowed down. The cumulative cured and discharged cases represented a positive trend of the epidemic. The larger the indicator value, the less the public will panic about the epidemic.

Previous studies mainly used daily new cases for time-delay correlation [16,22,27-33], while this study used new cases and confirmed cases. For confirmed, death, and cured discharge cases, new variables are the number of cases that increased in 1 day, and cumulative variables are the superposition of all the case data up to that day. The previously mentioned analysis showed that public attention was more consistent with new cases, which should be paid more attention to. Therefore, the content of epidemic information release should focus on the disclosure and interpretation of new cases and provide necessary explanations for possible causes of indicator disturbances so as to guide the public to correct risk perceptions and eliminate public panic. For example, the surge in new confirmed cases on February 12, 2020, was due to a change in statistical standards, with "clinically diagnosed cases" in Hubei included in the statistics of confirmed cases.

The early effect compared to new cases suggested that the BDI can be used as a sentinel in online infoveillance systems for infectious diseases and public health emergencies. The correlation analysis used in this study is the most common form of data monitoring, which is regularly applied to determine the relationship between internet-based and real-world data [8]. Gu et al [30] found that the erythromelalgia epidemic search index showed the uptrend about a week ahead of the official report because of the delayed reports from the local Center for Disease Control and Prevention. Future research can establish relevant models, including the vector autoregressive model, to predict the future trend of the epidemic based on past values of the real-world data [22,31].

Similarities and Differences of Public Attention Between the Hardest Hit Area and Other Areas

The hardest hit area was consistent with the whole country in the trend of BDI or the time lag cross-correlation analysis, except the peak of public attention across the country laid behind the hardest hit area by 2 days. That means that in the early stage of the COVID-19 pandemic, the public in the hardest hit area were more sensitive and alert to online epidemic information, while the public in other areas may have a lag in the attention to the epidemic. Besides, from the correlation between the BDI and real-world data, the national correlation coefficient was generally higher than that of the hardest hit area, indicating that the national public paid more attention to real-world data than the hardest hit area. In the spatial distribution of the BDI, the daily average BDI and per capita BDI of Hubei Province were not the highest, which also proved this point. That is to say, although the national public attention laid behind the hardest hit area, the level of attention was high. A possible reason for the delayed access to information is that when we focus on something, we will search for more of it. In other words, the public need for awareness is the internal motivation for people to use information systems to obtain needed information. In addition, the public will be concerned later than people in the "epicenter" of the epidemic because of the delay in getting information, such as untimely, incomplete information disclosure, or distortion of information transmission. When the public in other areas suspect that they have insufficient or asymmetric information, the truth's ambiguity will drive them to actively search for information to master sufficient COVID-19 knowledge [34], thus showing that the level of public attention is higher than that in the hardest hit area.

Conclusions

In this study, we found that the public searched for COVID-19 information showing the epidemic's progress. Moreover, people in the hardest hit area, with denser populations, larger internet user bases, and higher economic development levels, paid more attention to the epidemic's development. We could set the BDI as the sentinel in the online infoveillance system for infectious disease and public health emergencies. The change of the BDI was significantly earlier than the new cases, especially the new cured and discharged cases, which means the government needs to prevent and control the possible outbreak in advance according to the monitoring data and communicate the risks to

the public so as to ensure the physical and psychological health of the public in the epidemic.

Limitations

This study has several limitations. First, this study only focused on the attention of Baidu search engine users to COVID-19. It did not consider public attention in other search engines or social media such as Sina Weibo and WeChat, which can only reflect part of the public's attention to COVID-19. Second, since there was no uniform name for COVID-19 in the early stage of the epidemic, the public had a wide range of search terms. We only selected seven representative keywords to collect the BDI. Third, the Baidu search volume may be influenced by the media. Higgins et al [27] even pointed out that Google Trends and BDI

may have better reliability in defining the epidemiology for common diseases with minor media coverage or rare diseases and conditions with higher audiences. Fourth, this study cannot avoid the influence of searchers' age, occupation, and other demographic information. The average age of patients with COVID-19 is 51 years and nearly 80% of them are aged 30-69 years [35], but 90.2% of internet search engine users are younger than 50 years [36]. Moreover, people with different jobs may have different online search purposes and volumes. For example, experts, students, and doctors may conduct many searches due to work demands. However, due to Baidu's privacy protection policy, other demographic information such as the occupation of searchers is not provided, so we could not obtain more user-related information [37].

Acknowledgments

This study was funded by the National Natural Science Foundation of China (No 71704118).

Authors' Contributions

XG, YH, and RG designed the main concepts of this work. XG and YH performed data collection and wrote this paper. RG and MH edited and promoted the manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Indicators and situations of COVID-19 cases and China epidemic area division.

[DOCX File, 15 KB - [publichealth_v6i4e23098_app1.docx](#)]

References

1. WHO timeline - COVID-19. World Health Organization. 2020. URL: <https://www.who.int/zh/news-room/detail/27-04-2020-who-timeline---covid-19> [accessed 2020-06-22]
2. COVID-19 prevention and control: prevention and control dynamics. National Health Commission of the People's Republic of China. 2020. URL: <http://www.nhc.gov.cn/xcs/fkdt/202002/fdc6e8ea69e3401ca2b13573bcb7dfe0.shtml> [accessed 2020-06-22]
3. Wu F. Training of interdisciplinary public health personnel in the post-epidemic era [in Chinese]. Fudan University J Med Sci 2020 Jul 24 [FREE Full text] [doi: [10.3969/j.issn.1672-8467.2020.04.001](https://doi.org/10.3969/j.issn.1672-8467.2020.04.001)]
4. Majumder MS, Santillana M, Mekaru SR, McGinnis DP, Khan K, Brownstein JS. Utilizing nontraditional data sources for near real-time estimation of transmission dynamics during the 2015-2016 Colombian Zika virus disease outbreak. JMIR Public Health Surveill 2016 Jun 01;2(1):e30 [FREE Full text] [doi: [10.2196/publichealth.5814](https://doi.org/10.2196/publichealth.5814)] [Medline: [27251981](https://pubmed.ncbi.nlm.nih.gov/27251981/)]
5. Kandula S, Shaman J. Reappraising the utility of Google Flu Trends. PLoS Comput Biol 2019 Aug;15(8):e1007258 [FREE Full text] [doi: [10.1371/journal.pcbi.1007258](https://doi.org/10.1371/journal.pcbi.1007258)] [Medline: [31374088](https://pubmed.ncbi.nlm.nih.gov/31374088/)]
6. Santillana M, Nguyen AT, Dredze M, Paul MJ, Nsoesie EO, Brownstein JS. Combining search, social media, and traditional data sources to improve influenza surveillance. PLoS Comput Biol 2015 Oct;11(10):e1004513 [FREE Full text] [doi: [10.1371/journal.pcbi.1004513](https://doi.org/10.1371/journal.pcbi.1004513)] [Medline: [26513245](https://pubmed.ncbi.nlm.nih.gov/26513245/)]
7. Xu CJ, Zhang XY, Wang YG. Mapping of health literacy and social panic via web search data during the COVID-19 public health emergency: infodemiological study. J Med Internet Res 2020 Jul 02;22(7):e18831 [FREE Full text] [doi: [10.2196/18831](https://doi.org/10.2196/18831)] [Medline: [32540844](https://pubmed.ncbi.nlm.nih.gov/32540844/)]
8. Barros JM, Duggan J, Rebholz-Schuhmann D. The application of internet-based sources for public health surveillance (infoveillance): systematic review. J Med Internet Res 2020 Mar 13;22(3):e13680 [FREE Full text] [doi: [10.2196/13680](https://doi.org/10.2196/13680)] [Medline: [32167477](https://pubmed.ncbi.nlm.nih.gov/32167477/)]
9. Wilson K, Brownstein JS. Early detection of disease outbreaks using the internet. CMAJ 2009 Apr 14;180(8):829-831. [doi: [10.1503/cmaj.090215](https://doi.org/10.1503/cmaj.090215)] [Medline: [19364791](https://pubmed.ncbi.nlm.nih.gov/19364791/)]
10. Syndromic surveillance: reports from a national conference, 2003. Center for Disease Control and Prevention. URL: <https://www.cdc.gov/mmwr/preview/su5301toc.htm> [accessed 2020-08-12]

11. Eysenbach G. Infodemiology and infoveillance tracking online health information and cyberbehavior for public health. *Am J Prev Med* 2011 May;40(5 Suppl 2):S154-S158. [doi: [10.1016/j.amepre.2011.02.006](https://doi.org/10.1016/j.amepre.2011.02.006)] [Medline: [21521589](https://pubmed.ncbi.nlm.nih.gov/21521589/)]
12. Ortiz JR, Zhou H, Shay DK, Neuzil KM, Fowlkes AL, Goss CH. Monitoring influenza activity in the United States: a comparison of traditional surveillance systems with Google Flu Trends. *PLoS One* 2011 Apr 27;6(4):e18687 [FREE Full text] [doi: [10.1371/journal.pone.0018687](https://doi.org/10.1371/journal.pone.0018687)] [Medline: [21556151](https://pubmed.ncbi.nlm.nih.gov/21556151/)]
13. Liu BY, Wang Z, Qi XH, Zhang XQ, Chen HP. Assessing cyber-user awareness of an emerging infectious disease: evidence from human infections with avian influenza A H7N9 in Zhejiang, China. *Int J Infect Dis* 2015 Nov;40:34-36 [FREE Full text] [doi: [10.1016/j.ijid.2015.09.017](https://doi.org/10.1016/j.ijid.2015.09.017)] [Medline: [26432409](https://pubmed.ncbi.nlm.nih.gov/26432409/)]
14. Polgreen PM, Chen YL, Pennock DM, Nelson FD. Using internet searches for influenza surveillance. *Clin Infect Dis* 2008 Dec 01;47(11):1443-1448. [doi: [10.1086/593098](https://doi.org/10.1086/593098)] [Medline: [18954267](https://pubmed.ncbi.nlm.nih.gov/18954267/)]
15. Ginsberg J, Mohebbi MH, Patel RS, Brammer L, Smolinski MS, Brilliant L. Detecting influenza epidemics using search engine query data. *Nature* 2009 Feb 19;457(7232):1012-1014. [doi: [10.1038/nature07634](https://doi.org/10.1038/nature07634)] [Medline: [19020500](https://pubmed.ncbi.nlm.nih.gov/19020500/)]
16. Li CL, Chen LJ, Chen XY, Zhang MZ, Pang CP, Chen HY. Retrospective analysis of the possibility of predicting the COVID-19 outbreak from internet searches and social media data, China, 2020. *Euro Surveill* 2020 Mar;25(10) [FREE Full text] [doi: [10.2807/1560-7917.ES.2020.25.10.2000199](https://doi.org/10.2807/1560-7917.ES.2020.25.10.2000199)] [Medline: [32183935](https://pubmed.ncbi.nlm.nih.gov/32183935/)]
17. Han YY, Lie RK, Guo R. The internet hospital as a telehealth model in China: systematic search and content analysis. *J Med Internet Res* 2020 Jul 29;22(7):e17995 [FREE Full text] [doi: [10.2196/17995](https://doi.org/10.2196/17995)] [Medline: [32723721](https://pubmed.ncbi.nlm.nih.gov/32723721/)]
18. Yuan QY, Nsoesie EO, Lv BF, Peng G, Chunara R, Brownstein JS. Monitoring influenza epidemics in china with search query from baidu. *PLoS One* 2013;8(5):e64323. [doi: [10.1371/journal.pone.0064323](https://doi.org/10.1371/journal.pone.0064323)] [Medline: [23750192](https://pubmed.ncbi.nlm.nih.gov/23750192/)]
19. Gu H, Chen B, Zhu HH, Jiang T, Wang XY, Chen L, et al. Importance of Internet surveillance in public health emergency control and prevention: evidence from a digital epidemiologic study during avian influenza A H7N9 outbreaks. *J Med Internet Res* 2014 Jan 17;16(1):e20 [FREE Full text] [doi: [10.2196/jmir.2911](https://doi.org/10.2196/jmir.2911)] [Medline: [24440770](https://pubmed.ncbi.nlm.nih.gov/24440770/)]
20. Chen Y, Zhang YZ, Xu ZW, Wang XZ, Lu JH, Hu WB. Avian Influenza A (H7N9) and related internet search query data in China. *Sci Rep* 2019 Jul 18;9(1):10434. [doi: [10.1038/s41598-019-46898-y](https://doi.org/10.1038/s41598-019-46898-y)] [Medline: [31320681](https://pubmed.ncbi.nlm.nih.gov/31320681/)]
21. Gluskin RT, Johansson MA, Santillana M, Brownstein JS. Evaluation of Internet-based dengue query data: Google Dengue trends. *PLoS Negl Trop Dis* 2014 Feb;8(2):e2713. [doi: [10.1371/journal.pntd.0002713](https://doi.org/10.1371/journal.pntd.0002713)] [Medline: [24587465](https://pubmed.ncbi.nlm.nih.gov/24587465/)]
22. Li ZH, Liu T, Zhu GH, Lin HL, Zhang YH, He JF, et al. Dengue Baidu Search Index data can improve the prediction of local dengue epidemic: a case study in Guangzhou, China. *PLoS Negl Trop Dis* 2017 Mar;11(3):e0005354 [FREE Full text] [doi: [10.1371/journal.pntd.0005354](https://doi.org/10.1371/journal.pntd.0005354)] [Medline: [28263988](https://pubmed.ncbi.nlm.nih.gov/28263988/)]
23. COVID-19 prevention and control: epidemic notification. National Health Commission of the People's Republic of China. URL: http://www.nhc.gov.cn/xcs/yqtb/list_gzbd.shtml [accessed 2020-06-22]
24. Baidu Index. URL: <http://index.baidu.com/v2/main/index.html#/help> [accessed 2020-03-28]
25. Han XH, Wang JL, Zhang M, Wang XJ. Using social media to mine and analyze public opinion related to COVID-19 in China. *Int J Environ Res Public Health* 2020 Apr 17;17(8) [FREE Full text] [doi: [10.3390/ijerph17082788](https://doi.org/10.3390/ijerph17082788)] [Medline: [32316647](https://pubmed.ncbi.nlm.nih.gov/32316647/)]
26. Cervellin G, Comelli I, Lippi G. Is Google Trends a reliable tool for digital epidemiology? Insights from different clinical settings. *J Epidemiol Glob Health* 2017 Sep;7(3):185-189 [FREE Full text] [doi: [10.1016/j.jegh.2017.06.001](https://doi.org/10.1016/j.jegh.2017.06.001)] [Medline: [28756828](https://pubmed.ncbi.nlm.nih.gov/28756828/)]
27. Higgins TS, Wu AW, Sharma D, Illing EA, Rubel K, Ting JY, Snot Force Alliance. Correlations of online search engine trends with coronavirus disease (COVID-19) incidence: infodemiology study. *JMIR Public Health Surveill* 2020 May 21;6(2):e19702 [FREE Full text] [doi: [10.2196/19702](https://doi.org/10.2196/19702)] [Medline: [32401211](https://pubmed.ncbi.nlm.nih.gov/32401211/)]
28. Sun YT, Xiao F, Zhou Y, Tian GZ. Spatial-temporal distribution and influence mechanism of internet public attention on COVID-19: a case study on the Baidu Searching Index [in Chinese]. *Trop Geography* 2020 May;40(3):375-385. [doi: [10.13284/j.cnki.rddl.003244](https://doi.org/10.13284/j.cnki.rddl.003244)]
29. Chinese statistical yearbook-2019. Compiled by National Bureau of Statistics of China. URL: <http://www.stats.gov.cn/tjsj/ndsj/2019/indexch.htm> [accessed 2020-07-01]
30. Gu YZ, Chen FL, Liu T, Lv XJ, Shao ZM, Lin HL, et al. Early detection of an epidemic erythromelalgia outbreak using Baidu search data. *Sci Rep* 2015 Jul 28;5:12649. [doi: [10.1038/srep12649](https://doi.org/10.1038/srep12649)] [Medline: [26218589](https://pubmed.ncbi.nlm.nih.gov/26218589/)]
31. Huang RN, Luo GF, Duan QB, Zhang L, Zhang QP, Tang WM, et al. Using Baidu search index to monitor and predict newly diagnosed cases of HIV/AIDS, syphilis and gonorrhoea in China: estimates from a vector autoregressive (VAR) model. *BMJ Open* 2020 Mar 24;10(3):e036098. [doi: [10.1136/bmjopen-2019-036098](https://doi.org/10.1136/bmjopen-2019-036098)] [Medline: [32209633](https://pubmed.ncbi.nlm.nih.gov/32209633/)]
32. Li ZH, Liu T, Zhu GH, Lin HL, Zhang YH, He JF, et al. Dengue Baidu Search Index data can improve the prediction of local dengue epidemic: a case study in Guangzhou, China. *PLoS Negl Trop Dis* 2017 Mar;11(3):e0005354 [FREE Full text] [doi: [10.1371/journal.pntd.0005354](https://doi.org/10.1371/journal.pntd.0005354)] [Medline: [28263988](https://pubmed.ncbi.nlm.nih.gov/28263988/)]
33. Effenberger M, Kronbichler A, Shin JI, Mayer G, Tilg H, Perco P. Association of the COVID-19 pandemic with internet search volumes: a Google Trends analysis. *Int J Infect Dis* 2020 Jun;95:192-197 [FREE Full text] [doi: [10.1016/j.ijid.2020.04.033](https://doi.org/10.1016/j.ijid.2020.04.033)] [Medline: [32305520](https://pubmed.ncbi.nlm.nih.gov/32305520/)]
34. Mackuen M, Wolak J, Keele L, Marcus GE. Civic engagements: resolute partisanship or reflective deliberation. *Am J Polit Sci* 2010 Apr 09;54(2):440-458. [doi: [10.1111/j.1540-5907.2010.00440.x](https://doi.org/10.1111/j.1540-5907.2010.00440.x)]

35. China-World Health Organization COVID-19 Joint Expert Investigation Team: Novel Coronavirus has not mutated significantly. China Central Television. 2020. URL: <http://news.cctv.com/2020/02/25/ARTIJ13jXV5mzraAXil4yrCa200225.shtml> [accessed 2020-08-12]
36. Research report on search engine usage of Chinese netizens in 2019. China Internet Network Information Center. URL: <https://www.cnnic.cn/hlwfzyj/hlwxzbg/ssbg/201910/P020191025506904765613.pdf> [accessed 2020-08-12]
37. Baidu privacy protection statement. Baidu. URL: <https://www.baidu.com/duty/yinsiquan.html> [accessed 2020-08-12]

Abbreviations

BDI: Baidu Index

Edited by G Eysenbach; submitted 31.07.20; peer-reviewed by H Liang, W Yaogang; comments to author 11.08.20; revised version received 13.08.20; accepted 21.09.20; published 22.10.20.

Please cite as:

Gong X, Han Y, Hou M, Guo R

Online Public Attention During the Early Days of the COVID-19 Pandemic: Inveillance Study Based on Baidu Index

JMIR Public Health Surveill 2020;6(4):e23098

URL: <http://publichealth.jmir.org/2020/4/e23098/>

doi: [10.2196/23098](https://doi.org/10.2196/23098)

PMID: [32960177](https://pubmed.ncbi.nlm.nih.gov/32960177/)

©Xue Gong, Yangyang Han, Mengchi Hou, Rui Guo. Originally published in JMIR Public Health and Surveillance (<http://publichealth.jmir.org>), 22.10.2020. This is an open-access article distributed under the terms of the Creative Commons Attribution License (<https://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in JMIR Public Health and Surveillance, is properly cited. The complete bibliographic information, a link to the original publication on <http://publichealth.jmir.org>, as well as this copyright and license information must be included.

Original Paper

Concerns and Misconceptions About the Australian Government's COVIDSafe App: Cross-Sectional Survey Study

Rae Thomas¹, PhD; Zoe A Michaleff¹, PhD; Hannah Greenwood¹, BSc; Eman Abukmail¹, MD; Paul Glasziou¹, MD, PhD

Institute for Evidence-Based Healthcare, Bond University, Robina, Australia

Corresponding Author:

Rae Thomas, PhD

Institute for Evidence-Based Healthcare

Bond University

University Drive

Robina, 4229

Australia

Phone: 61 5595 5521

Email: rthomas@bond.edu.au

Abstract

Background: Timely and effective contact tracing is an essential public health measure for curbing the transmission of COVID-19. App-based contact tracing has the potential to optimize the resources of overstretched public health departments. However, its efficiency is dependent on widespread adoption.

Objective: This study aimed to investigate the uptake of the Australian Government's COVIDSafe app among Australians and examine the reasons why some Australians have not downloaded the app.

Methods: An online national survey, with representative quotas for age and gender, was conducted between May 8 and May 11, 2020. Participants were excluded if they were a health care professional or had been tested for COVID-19.

Results: Of the 1802 potential participants contacted, 289 (16.0%) were excluded prior to completing the survey, 13 (0.7%) declined, and 1500 (83.2%) participated in the survey. Of the 1500 survey participants, 37.3% (n=560) had downloaded the COVIDSafe app, 18.7% (n=280) intended to do so, 27.7% (n=416) refused to do so, and 16.3% (n=244) were undecided. Equally proportioned reasons for not downloading the app included privacy (165/660, 25.0%) and technical concerns (159/660, 24.1%). Other reasons included the belief that social distancing was sufficient and the app was unnecessary (111/660, 16.8%), distrust in the government (73/660, 11.1%), and other miscellaneous responses (eg, apathy and following the decisions of others) (73/660, 11.1%). In addition, knowledge about COVIDSafe varied among participants, as some were confused about its purpose and capabilities.

Conclusions: For the COVIDSafe app to be accepted by the public and used correctly, public health messages need to address the concerns of citizens, specifically privacy, data storage, and technical capabilities. Understanding the specific barriers preventing the uptake of contact tracing apps provides the opportunity to design targeted communication strategies aimed at strengthening public health initiatives, such as downloading and correctly using contact tracing apps.

(*JMIR Public Health Surveill* 2020;6(4):e23081) doi:[10.2196/23081](https://doi.org/10.2196/23081)

KEYWORDS

health; policy; COVID-19; digital tracing app; COVIDSafe

Introduction

COVID-19 is a viral disease caused by a newly discovered strain of coronaviruses. People affected by the disease commonly present with fever, cough, and shortness of breath. This disease can also cause death, with varying rates observed in different countries. In Australia, the first case of COVID-19 was

confirmed in late January 2020, with the first wave occurring between March and May, 2020. In the absence of a vaccine, nondrug interventions for preventing COVID-19 and any other future infectious outbreaks are critical [1,2]. The public has been asked to practice preventive behaviors, such as hand hygiene, physical distancing, quarantining, and getting tested when sick. These behaviors are being promoted by national and international public health organizations through

population-based communication strategies. Alongside individually practiced prevention strategies are population-based strategies such as contact tracing, which is critical for preventing and slowing the spread of disease.

To improve public health contact tracing and the speed at which it occurs, several countries have introduced app-based contact tracing. Contact tracing apps vary in design, from reporting symptoms to public health authorities [3] to allowing access to phone data after testing positive for COVID-19 [4]. They also vary in whether the data are centralized [5]. Furthermore, contact tracing apps in current use have had varying degrees of success [3,6]. Since the Australian Government launched the COVIDSafe app in late April 2020 [4], over 6 million Australians (almost 25%) have downloaded the app. However, worldwide concerns have been raised about the privacy and ethics of this digital approach [7], which may hamper app downloads and decrease app effectiveness. This has been reflected in the Australian uptake of the COVIDSafe app; following its initial release, downloads have progressively decreased. Currently, Australian downloads are short of the 40% proposed target for the app to be effective, and this has not been anticipated to change without further government intervention to increase uptake.

App-based contact tracing requires public cooperation. Individuals are required to install the app, keep Bluetooth functions on, have the app activated or open on their phones, and carry their phones with them when outside of their home. This sounds simple, but when considered from a behavior change perspective, these behaviors are complex and need to be performed together to optimize contact tracing functionality [8]. To identify behavior change techniques for improving the uptake of app-based contact tracing, we first need to understand people's reasons for not downloading the app. In this study, we aimed to investigate the uptake of the Australian Government's COVIDSafe app among Australians, identify Australians' understanding of the purpose and capabilities of the app, and explore the reasons why some Australians chose not to download the app.

Methods

Participants were recruited for a national, cross-sectional, online survey by the panel provider, Dynata. The use of a panel provider for online research provides confidence in attaining a representative sample of the required size and allows for quick completion of time-sensitive projects. The panel provider adheres to our quotas for age, gender, and state/territory of residence, ensuring that our sample is representative of the broader population. Through Dynata, participants received points for completing the survey, which may be used for gift vouchers, donations, or cash redemption. Our sample was representative of all Australian states and territories and met our quotas for age and gender. Participants were included in our study if aged ≥ 18 years. Participants were excluded if they had, or thought they had, COVID-19. They were also excluded

if they were health care professionals, as this group may have systematic differences in knowledge of COVID-19 compared to the general Australian population.

Prior to screening, potential participants read detailed study information, including eligibility criteria, what the study involved, and privacy and confidentiality rights. Participants were informed that commencing the survey indicated their informed consent to participate in this study. Ethics approval was obtained from the Bond University Human Research Ethics Committee (#RT03008).

All participants were asked whether they had downloaded, or intended to download, the COVIDSafe app. If they responded "unsure" or "no intention to download," they were asked to provide a reason for their response. We qualitatively coded the reasons for inaction and uncertainty and conducted a thematic content analysis of open-ended responses. Uninformative responses, such as "not sure," were not coded. If multiple concerns were mentioned, only the first response was coded. The code frame was initially developed by RT, and then discussed and refined by the other authors. Afterward, 1 author (RT) completed the qualitative analysis of all responses. Participants then rated their strength of agreement for 6 statements related to the app's purpose and capabilities using a 5-point Likert scale (1=strongly disagree to 5=strongly agree; option for "don't know" response was available). The survey items and response scale are available in [Multimedia Appendix 1](#).

Results

Of the 1802 potential participants contacted, 289 (16.0%) were screened as ineligible prior to completing the survey and were excluded, 13 (0.7%) declined, and 1500 (83.2%) participated in the survey. There was representation across all adult age groups and sexes (50.0% male), and education levels were distributed evenly (high school and technical and further education qualification or lower: 735/1500, 49.0%; tertiary qualification: 765/1500, 51.0%) ([Table 1](#)).

Of the 1500 survey participants, 37.3% (560/1500) said they downloaded the COVIDSafe app, 18.7% (280/1500) had intended to, 27.7% (416/1500) refused, and 16.3% (244/1500) were undecided. Of the 660 who refused or were undecided, 25.0% (n=165) cited privacy concerns as their primary reason. For example, many distrusted the security of the app; some participants believed that the COVIDSafe app was not safe and that it could be hacked, resulting in their information being used without their authority. Another 24.1% (159/660) cited technical problems, such as phones being too old or limitations in data consumption and storage space. Other reasons for being undecided or refusing to download the app included the belief that social distancing was sufficient and the app was unnecessary, distrust in the government, questioning the app's effectiveness, wanting to explore more information before deciding, and other miscellaneous responses, such as apathy and following the decisions of others ([Table 2](#)).

Table 1. Participants' characteristics (N=1500).

Characteristics	Values, n (%)
Female	750 (50.0)
Age (years)	
18-24	171 (11.4)
25-34	264 (17.6)
35-4	239 (15.9)
45-54	223 (14.9)
55-64	222 (14.8)
65-74	227 (15.1)
≥75	154 (10.3)
Education	
High school graduate or lower	459 (30.6)
Trade certificate (I-IV)	276 (18.4)
Tertiary	765 (51.0)
Australian states and territories	
Queensland	302 (20.1)
New South Wales	471 (31.4)
Australian Capital Territory	29 (1.9)
Northern Territory	9 (0.6)
Western Australia	160 (10.7)
Victoria	382 (25.5)
Tasmania	34 (2.3)
South Australia	113 (7.5)
Aboriginal or Torres Strait Islander	
Yes	17 (1.1)
No	1471 (98.1)
Prefer not to say	12 (0.8)
Born in Australia	1049 (69.9)

Table 2. Reasons for not downloading the COVIDSafe app (N=660).

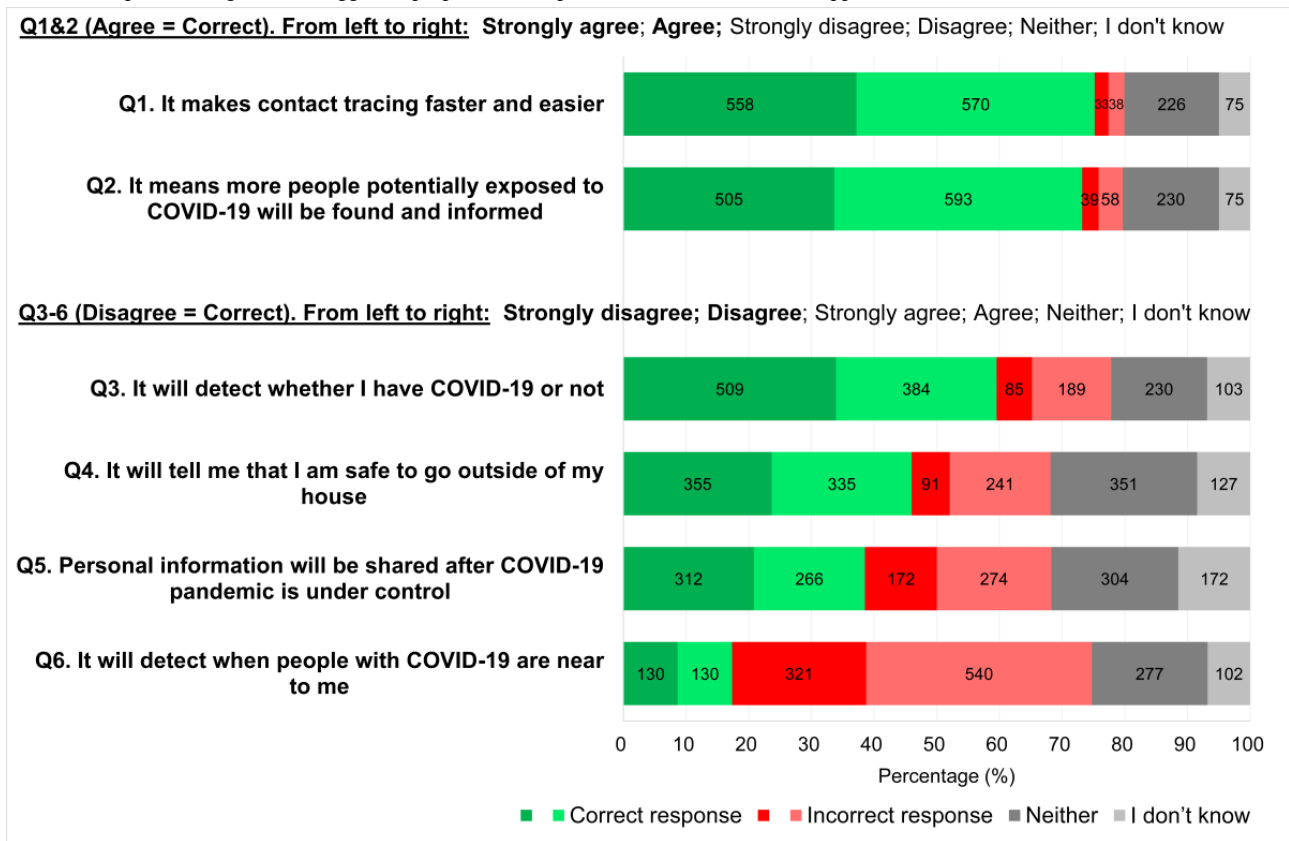
Reasons for not downloading	Values, n (%)
Privacy concerns	165 (25.0)
Technical problems	159 (24.1)
App is unnecessary	111 (16.8)
Distrust in the government	73 (11.1)
Questioning effectiveness of app	46 (7.0)
Need more information before deciding	33 (5.0)
Uncoded miscellaneous reasons	73 (11.1)

With respect to the app's intended purpose and capabilities, almost 75% of participants correctly agreed that the app would make contact tracing faster and easier (strongly agree: 558/1500, 37.2%; agree: 570/1500, 38.0%), and almost 72% correctly agreed that more people who were potentially exposed to COVID-19 would be found and informed (strongly agree:

505/1500, 33.7%; agree 593/1500, 39.5%) (Figure 1). In contrast, almost 50% of participants incorrectly thought that their personal information would be shared after the pandemic (strongly agree: 172/1500, 11.5%; agree: 274/1500, 18.3%; neither: 304/1500, 20.3%), and almost 72% incorrectly thought that the app would detect when people with COVID-19 were

near them (strongly agree: 321/1500, 21.4%; agree: 540/1500, 36.0%; neither: 227/1500, 15.1%) (Figure 1). Interestingly, participants were divided in knowing whether the app would inform them that it was safe to leave their house (Figure 1).

Figure 1. Participants' ratings for the suggested purposes and capabilities of the COVIDSafe app (N=1500).



In Table 3, we descriptively report the differences in intentions to download the COVIDSafe app between age groups. We did not perform statistical analyses on these subgroups. However, there appears to be little difference between age groups in terms of the number of app downloads and the number of people who intended to download the app. For example, in the youngest

age group, 60.8% (104/171) of our sample had already downloaded, or intended to download, the app, and 58.4% (90/154) of participants in the oldest age group had done, or intended to do, the same (Table 3). This pattern was also observed for those who decided to not download the app or were undecided.

Table 3. Age groups and intentions to download the COVIDSafe app.

Age group (years)	Downloaded, n (%)	Intend to download, n (%)	Refused to download, n (%)	Unsure, n (%)	Total
18-24	52 (30.4)	52 (30.4)	50 (29.2)	17 (9.9)	171
25-34	94 (35.6)	69 (26.1)	57 (21.6)	44 (16.7)	264
35-44	91 (38.1)	39 (16.3)	67 (28.0)	42 (17.6)	239
45-54	82 (36.8)	33 (14.8)	70 (31.4)	38 (17.0)	223
55-64	82 (36.9)	31 (14.0)	65 (29.3)	44 (19.8)	222
65-74	97 (42.7)	28 (12.3)	65 (28.6)	37 (16.3)	227
≥75	62 (40.3)	28 (18.2)	42 (27.3)	22 (14.3)	154
Total ^a	560 (37.3)	280 (18.7)	416 (27.7)	244 (16.3)	1500

^aTotal n for each download behavior and % of total sample.

Discussion

Timely and effective contact tracing is an essential public health measure for curbing the transmission of COVID-19. Contact tracing apps are controversial in their design and level of effectiveness [3,5,6], but they might have the potential to prevent

widespread community transmission and optimize the resources of overstretched public health organizations [9]. An important driver for their efficiency is widespread public adoption [9]. Our study aimed to examine Australian participants' understanding of the Australian Government's COVIDSafe app and explore the reasons why some Australians chose not to

download the app. Primarily, we found that while most people correctly understood the intended purpose and capabilities of the app, there was some crucial misunderstandings about the contact tracing limits of the software (ie, whether the app can detect when a person is close to someone with COVID-19 and whether the app can let people know when it is safe to leave home). Among those who were undecided or refused to download the app, the main reasons for hesitation centered around privacy and technological barriers, which are key concerns that need to be addressed if uptake of the app is to increase.

In total, 37.3% (560/1500) of our sample said they had downloaded the app and 18.7% (280/1500) intended to. This proportion is concordant with another Australian survey with a smaller online sample (N=439), in which 44.0% of participants reported downloading the COVIDSafe app [10]. However, based on other surveys in which participants were asked whether they intended to download hypothetical apps, the acceptability of contact tracing apps is higher in other countries. For example, in a recent online survey from Ireland (N>8000) [11], when asked about downloading a contact tracing app that was not yet available, 58% of participants said they would download it and 25% said they probably would [8]. Additionally, in another online survey with almost 6000 participants from 5 countries (ie, the United Kingdom, Germany, Italy, France, and the United States), 75% of participants said they definitely or probably would install a contact tracing app [12]. It would be interesting to see whether people will actually follow through with their intentions to download a contact tracing app.

With regard to open-ended text responses, 25% of participants in our study who did not download the COVIDSafe app were concerned about privacy. This is lower than the 31% in the smaller Australian study [10] and the 41% in the Irish study [11] who believed privacy was a problem. The differences in these percentages may be due to the free-text responses available in our survey, as the other studies used a list of options for participants' responses. Additionally, compared to the 11.1% of participants in our survey who did not download the app because they distrusted the government, there was more distrust in postpandemic government surveillance with Irish participants (33%) [11] and participants in the cross-country survey (42%) [12]. When considering communication strategies for improving contact tracing app downloads and use, better communication approaches are needed to put the public's concerns about privacy and the government at ease.

Our study also reveals that there are missed communication opportunities for correcting erroneous beliefs about the

capabilities of the COVIDSafe app. Over half of our participants (810/1500, 54.0%) thought the COVIDSafe app would or might tell them when it was safe to leave the house, and 40.5% (607/1500) thought it would or might tell them whether they had COVID-19 (Figure 1). Addressing these perceptions and issues about the capabilities of the app with public messaging is important for achieving sufficient uptake of contact tracing apps.

Based on reviewer feedback and the fact that older adults are disproportionately affected by COVID-19, we performed a posthoc analysis to descriptively examine the uptake of the app by age. App downloads appeared to increase with age, with the 65-74-year and ≥75-year age groups having the highest proportion of downloads, and this trend may reflect older adults' vulnerability to COVID-19. However, when the number of people who downloaded or intended to download the app were combined, the differences between age groups were much smaller. Almost one-third (416/1500, 27.7%) of participants, regardless of age, chose not to download the app.

To our knowledge, this study is the first to qualitatively analyze open-ended text responses to barriers for downloading a contact tracing app. Compared to having participants select a response from a list of predefined options, our approach decreases potential researcher biases and strengthens the ability to inform communication techniques for improving app uptake. To further minimize bias, we deliberately recruited a sample with representation from all Australian states and territories and quotas for age and gender. We believe this strategy improved the generalizability of our findings to the broader Australian population. However, we did not assess cultural and linguistic diversity. Therefore, the generalizability of our findings is limited to Australians, and our results may not reflect the perceptions of individuals whose primary language is not English.

Although the level of effectiveness of contact tracing is still unclear [3,6], apps have been used in various countries to help with both contact tracing [4] and medical management of COVID-19 cases [13]. Their utility comes from being used as an adjunct contact tracing strategy alongside public health staff, particularly when community transmissions are high. For apps to be accepted by the public and used correctly, we need to better communicate concerns about privacy, data storage, and technical capabilities. The lessons learned during the COVID-19 pandemic will be invaluable for inevitable future infectious outbreaks.

Acknowledgments

RT, ZAM, and HG are supported by a National Health and Medical Research Council Program grant (#1106452). PG is supported by an National Health and Medical Research Council Research Fellowship (#1080042).

Conflicts of Interest

None declared.

Multimedia Appendix 1

Table detailing the COVIDSafe survey items and scores.

[DOC File, 15 KB - [publichealth_v6i4e23081_app1.DOC](#)]

References

1. Hoffmann T, Glasziou P. What if the vaccine or drugs don't save us? Plan B for coronavirus means research on alternatives is urgently needed. The Conversation. Online: The Conversation; 2020 Apr 21. URL: <https://theconversation.com/what-if-the-vaccine-or-drugs-dont-save-us-plan-b-for-coronavirus-means-research-on-alternatives-is-urgently-needed-136833> [accessed 2020-10-26]
2. Michie S, West R. Behavioural, environmental, social, and systems interventions against covid-19. *BMJ* 2020 Jul 28;370:m2982. [doi: [10.1136/bmj.m2982](https://doi.org/10.1136/bmj.m2982)] [Medline: [32723732](https://pubmed.ncbi.nlm.nih.gov/32723732/)]
3. Kendall M, Milsom L, Abeler-Dorner L, Wymant C, Ferretti L, Briers M, et al. COVID-19 incidence and R decreased on the Isle of Wight after the launch of the Test, Trace, Isolate programme. medRxiv Preprint posted online on July 14, 2020. [doi: [10.1101/2020.07.12.20151753](https://doi.org/10.1101/2020.07.12.20151753)]
4. Australian Government, Department of Health. COVIDSafe app. Health. URL: <https://www.health.gov.au/resources/apps-and-tools/covidsafe-app> [accessed 2020-10-26]
5. Culnane C, Leins K, Rubinstein BI. Tracking, tracing, trust: contemplating mitigating the impact of COVID-19 through technological interventions. *Med J Aust* 2020 Jul;213(2):94-94.e1 [FREE Full text] [doi: [10.5694/mja2.50683](https://doi.org/10.5694/mja2.50683)] [Medline: [32583470](https://pubmed.ncbi.nlm.nih.gov/32583470/)]
6. Wise J. Covid-19: Test and trace system is not fit for purpose, says Independent SAGE. *BMJ* 2020 Jun 09;369:m2302. [doi: [10.1136/bmj.m2302](https://doi.org/10.1136/bmj.m2302)] [Medline: [32518067](https://pubmed.ncbi.nlm.nih.gov/32518067/)]
7. Abeler J, Bäcker M, Buermeyer U, Zillessen H. COVID-19 Contact Tracing and Data Protection Can Go Together. *JMIR Mhealth Uhealth* 2020 Apr 20;8(4):e19359 [FREE Full text] [doi: [10.2196/19359](https://doi.org/10.2196/19359)] [Medline: [32294052](https://pubmed.ncbi.nlm.nih.gov/32294052/)]
8. Michie S, Atkins L, West R. The behaviour change wheel. In: *The Behaviour Change Wheel A Guide to Designing Interventions*. Great Britain: Silverback Publishing; 2014:1003-1010.
9. Currie DJ, Peng CQ, Lyle DM, Jameson BA, Frommer MS. Stemming the flow: how much can the Australian smartphone app help to control COVID-19? *Public Health Res Pract* 2020 Jun 30;30(2) [FREE Full text] [doi: [10.17061/phrp3022009](https://doi.org/10.17061/phrp3022009)] [Medline: [32601652](https://pubmed.ncbi.nlm.nih.gov/32601652/)]
10. Garret P, White J, Little D, Perfors A, Kashima Y, Lewandowsky S, et al. A Representative Sample of Australian Participant's Attitudes Towards the COVIDSafe App. GitHub. URL: <https://paulgarretphd.github.io/Site/Wave3PrelimAnalysis.html> [accessed 2020-10-26]
11. O'Callaghan ME, Buckley J, Fitzgerald B, Johnson K, Laffey J, McNicholas B, et al. A national survey of attitudes to COVID-19 digital contact tracing in the Republic of Ireland. Research Square Preprint posted online on July 10, 2020. [FREE Full text] [doi: [10.21203/rs.3.rs-40778/v1](https://doi.org/10.21203/rs.3.rs-40778/v1)]
12. Altmann S, Milsom L, Zillessen H, Blasone R, Gerdon F, Bach R, et al. Acceptability of app-based contact tracing for COVID-19: Cross-country survey evidence. medRxiv Preprint posted online on May 8, 2020. [FREE Full text] [doi: [10.1101/2020.05.05.20091587](https://doi.org/10.1101/2020.05.05.20091587)]
13. Echeverría P, Mas Bergas MA, Puig J, Isnard M, Massot M, Vedia C, et al. COVIDApp as an Innovative Strategy for the Management and Follow-Up of COVID-19 Cases in Long-Term Care Facilities in Catalonia: Implementation Study. *JMIR Public Health Surveill* 2020 Jul 17;6(3):e21163 [FREE Full text] [doi: [10.2196/21163](https://doi.org/10.2196/21163)] [Medline: [32629425](https://pubmed.ncbi.nlm.nih.gov/32629425/)]

Edited by T Sanchez; submitted 02.08.20; peer-reviewed by V Lewis, D Juzwishin; comments to author 18.09.20; revised version received 09.10.20; accepted 12.10.20; published 04.11.20.

Please cite as:

Thomas R, Michaleff ZA, Greenwood H, Abukmail E, Glasziou P
Concerns and Misconceptions About the Australian Government's COVIDSafe App: Cross-Sectional Survey Study
JMIR Public Health Surveill 2020;6(4):e23081
URL: <http://publichealth.jmir.org/2020/4/e23081/>
doi:[10.2196/23081](https://doi.org/10.2196/23081)
PMID:[33048826](https://pubmed.ncbi.nlm.nih.gov/33048826/)

©Rae Thomas, Zoe A Michaleff, Hannah Greenwood, Eman Abukmail, Paul Glasziou. Originally published in *JMIR Public Health and Surveillance* (<http://publichealth.jmir.org>), 04.11.2020. This is an open-access article distributed under the terms of the Creative Commons Attribution License (<https://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in *JMIR Public Health and Surveillance*,

is properly cited. The complete bibliographic information, a link to the original publication on <http://publichealth.jmir.org>, as well as this copyright and license information must be included.

Original Paper

Public Perception of the COVID-19 Pandemic on Twitter: Sentiment Analysis and Topic Modeling Study

Sakun Boon-Itt¹, PhD; Yukolpat Skunkan², MD

¹Department of Operations Management, Center of Excellence in Operations and Information Management, Thammasat Business School, Thammasat University, Bangkok, Thailand

²Bangkok Christian Hospital, Bangkok, Thailand

Corresponding Author:

Sakun Boon-Itt, PhD

Department of Operations Management, Center of Excellence in Operations and Information Management

Thammasat Business School

Thammasat University

2 Prachan Road

Pranakorn

Bangkok, 10240

Thailand

Phone: 66 26132200

Email: sboonitt@tu.ac.th

Abstract

Background: COVID-19 is a scientifically and medically novel disease that is not fully understood because it has yet to be consistently and deeply studied. Among the gaps in research on the COVID-19 outbreak, there is a lack of sufficient infoveillance data.

Objective: The aim of this study was to increase understanding of public awareness of COVID-19 pandemic trends and uncover meaningful themes of concern posted by Twitter users in the English language during the pandemic.

Methods: Data mining was conducted on Twitter to collect a total of 107,990 tweets related to COVID-19 between December 13 and March 9, 2020. The analyses included frequency of keywords, sentiment analysis, and topic modeling to identify and explore discussion topics over time. A natural language processing approach and the latent Dirichlet allocation algorithm were used to identify the most common tweet topics as well as to categorize clusters and identify themes based on the keyword analysis.

Results: The results indicate three main aspects of public awareness and concern regarding the COVID-19 pandemic. First, the trend of the spread and symptoms of COVID-19 can be divided into three stages. Second, the results of the sentiment analysis showed that people have a negative outlook toward COVID-19. Third, based on topic modeling, the themes relating to COVID-19 and the outbreak were divided into three categories: the COVID-19 pandemic emergency, how to control COVID-19, and reports on COVID-19.

Conclusions: Sentiment analysis and topic modeling can produce useful information about the trends in the discussion of the COVID-19 pandemic on social media as well as alternative perspectives to investigate the COVID-19 crisis, which has created considerable public awareness. This study shows that Twitter is a good communication channel for understanding both public concern and public awareness about COVID-19. These findings can help health departments communicate information to alleviate specific public concerns about the disease.

(*JMIR Public Health Surveill* 2020;6(4):e21978) doi:[10.2196/21978](https://doi.org/10.2196/21978)

KEYWORDS

COVID-19; Twitter; social media; infoveillance; infodemiology; infodemic; data; health informatics; mining; perception; topic modeling

Introduction

In the course of history, there have been many infectious disease outbreaks in the human population, causing both loss of life and damage to economies [1]. At the end of 2019, the World Health Organization (WHO) reported a cluster of cases of pneumonia in Wuhan. The cause of this pneumonia was later defined by the WHO as COVID-19. COVID-19 is a new infectious disease that is spread by respiratory droplets and contact and is generally infectious to human beings [2]. COVID-19 has had an unprecedented impact worldwide, with more than 10,000,000 confirmed cases and more than 500,000 reported deaths in more than 200 countries [3]. On January 30, 2020, the WHO reported that COVID-19 was a public health emergency of international concern [4].

Social media platforms can provide rich and useful information to predict and explain the characteristics and status of disease outbreaks [5]. Text mining can be used to extract health information from social media platforms such as Twitter [6]. Twitter data enable researchers to obtain large samples of user-generated content, thereby garnering insights to inform early response strategies. Social media data text mining has been used to track diseases and assess public awareness concerning health issues, enabling disease forecasting [7]. Text analysis of Twitter data is one of the most important areas of focus in medical informatics research [8].

COVID-19 is a scientifically and medically novel disease that is not fully understood, as it has yet to be consistently and deeply studied [9]. This study can be challenging because in the initial stage of an outbreak, most data are incomplete due to inadequate diagnostic and testing capabilities. Most of the data reported are epidemiological, such as data from medical units or scientific laboratories. The use of social media information to analyze syndromic surveillance, focusing on public health-related concerns using web-based information and content, is essential [10]. One important reason is that during an outbreak, social media plays a critical role, as these platforms reflect real-time public panic through comments. Twitter, one of these social media platforms, has often served as a communication modality during disease outbreaks [11]. Twitter provides rich information to increase public awareness and inform people about outbreak locations. This is very useful to provide insight regarding the issues related to infectious disease outbreaks.

Regarding COVID-19, there is a lack of social media data-based research studying the spread of the disease, the behavioral awareness of the public, and emergent conversations on COVID-19. Taking research published in 2020 as examples, Shen et al [12] studied mentions of symptoms and diseases on social media to predict COVID-19 case counts, and Huang et al [13] analyzed social media posts to study the characteristics of COVID-19 patients in China. However, both these studies focused primarily on China. Moreover, Park et al [14] addressed information transmission networks and news-sharing behaviors on Twitter regarding COVID-19 in Korea only. Abd-Alrazaq et al [15] conducted an infoveillance study on aspects of the COVID-19 pandemic, aiming to study the main topics of discussion related to the disease. Chen et al [16] presented basic

statistics that tracked only Twitter activity responding and reacting to COVID-19-related events. Lwin et al [17] studied Twitter users' public emotional responses to COVID-19, focusing on four basic emotions only. However, these previous studies did not use Twitter data to address conclusive themes, nor did they perform sentiment analysis during the timeline of COVID-19 in its initial stage. These missing data are important because themes and sentiment analysis can provide a wider overview of public awareness [18]. The evolution of sentiment analysis of Twitter data since the early stages of the COVID-19 pandemic has not yet been fully presented. Greater understanding and public awareness of the pandemic are still needed.

Building on previous research, this study posits that theme and sentiment analysis of posts on Twitter in the early stages of the COVID-19 pandemic can aid understanding of the emotions, beliefs, and thoughts of the general public. This is important to enable policy makers to increase situational awareness of COVID-19 and make suitable interventions during impending outbreaks. The objective is to answer two research questions: (1) What is the level of public awareness in terms of sentiments and emotions toward COVID-19? and (2) What are the emergent topical themes and discourses regarding COVID-19?

Methods

Data Collection

This study was conducted in two stages: (1) data collection using the Twitter streaming application programming interface (API) to collect COVID-19-related posts in the English language, and (2) data analysis to identify trends, keywords, and themes. The objective of this study was to answer questions relating to themes, public concerns, and sentiments regarding the COVID-19 pandemic through social media analytics. The data were collected from Twitter to build a database on the pattern of the COVID-19 epidemic. Data from Twitter are acceptable for research, being very rich and useful [19]. Twitter is a medium in which millions of people can express their views on any issue or topic. For example, during previous events such as natural disasters or disease outbreaks, people used Twitter to express their feelings [20,21]; this has been particularly true during the global epidemic of COVID-19. This study collected tweets using the Twitter streaming API, which is a Java application that can connect to a Twitter stream and store the raw data in a MySQL database. The Twitter streaming API enables nearly real-time access to the global stream of public tweets that match specified keywords. To access the API, it was necessary to be signed up on Twitter and log into the developer Twitter account. The next step was developing an application or API to provide the keys and tokens for using it in the programming environment.

The tweet database was created by specifying keywords and metadata such as language, source, data range, and location. This search used keywords and specific hashtags (#) such as *coronavirus*, *covid_19*, *2019-nCov*, and *covid-19* in the English language using the searchtweets tool [22]. The scope of the keywords and specific hashtags determines which tweets are delivered on the stream. This study employed a purposive

sampling approach of tweets by active Twitter users between December 13, 2019, and March 9, 2020 (approximately covering the most recent days in the Twitter database). The main objective was to answer the research questions between the end of 2019 and the beginning of 2020; during this period, the outbreak started in China and then spread to Europe and America. This particular period is important to examine public concerns relating to the early COVID-19 outbreak.

The aim of our analysis of COVID-19 pandemic trends in English-language tweets was not to determine the volume of daily tweets. Our purpose was to measure the intensity of Twitter activities relating to COVID-19 with the stipulated keywords based on tweets that received retweets, representing conversation and content sharing about COVID-19 on Twitter [23]. This approach is effective because it will filter out low activity and outliers that are not useful. A sample of the top 1000 tweets with retweets as a proxy for Twitter activity was taken. Because the data were sampled on a daily basis over a period of 3 months, the granularity was sufficient to measure the changes in activity from day to day. This sampling process was repeated to collect a total of 107,990 tweets during this time period.

Data Analysis

This study employed three data preparation steps: sampling, data collection, and preprocessing of raw data. To start data processing, the tweet texts were subjected to a series of functions to remove URLs, emojis, special characters, retweets, hash symbols, and hyperlinks pointing to websites; this process also enabled us, as much as possible, to exclude mentions of related diseases that would contaminate the results. Stop words in English (eg, *for*, *the*, *is*) were also removed, as were words such as *corona* or *virus* that may relate to other topics [24]. In addition, the tweet texts were converted to lower case, and words were changed to their root forms (eg, *viruses* to *virus*). The tweets were then converted into a corpus (text mining structure); we also created a document-term matrix and calculated the term frequency-inverse document frequency (TF-IDF), which is a numerical statistic used to reflect the importance of a word in a corpus. To obtain the output of the scenario, the tweet data were analyzed; to extract the tweet data, the Twitter API was used.

The data analysis not only focused on the overall picture of COVID-19 but was also scoped down based on keywords and specific hashtags such as *symptoms*, *outbreak*, and *pandemic*. The data analysis was conducted using Python software and RStudio. As mentioned earlier, three types of analysis were used to answer both research questions. First, the data analysis focused on the frequencies of single words (unigram) in the corpus of the text mining structure and visualized these frequencies through word clouds to display the most common topics. Content analysis can be used to analyze words or messages to show that events occurred after an incident or to study symptoms using word frequency counts, a widely used method in content analysis, as the rules for determining themes. The analysis also included time series using “retweet_count” and “favorite_count” as proxies of the intensity of social media activity on Twitter relating to COVID-19 to observe trends and timelines.

Second, sentiment analysis, a natural language processing (NLP) approach, was used to categorize the sentiments appearing in Twitter messages [25]. This approach involved analyzing the keywords appearing in the search topics and exploring the sentiments expressed in each topic related to COVID-19, including word frequency statistics and word clouds. For a more detailed analysis of the tweets, the emotional quotients associated with the tweets were analyzed. Sentiment analysis using the National Research Council (NRC) sentiment lexicon enabled us to examine the expression of 10 terms related to basic emotions: *anger*, *anticipation*, *disgust*, *fear*, *joy*, *negative*, *positive*, *sadness*, *surprise*, and *trust* [26,27]. The terms *positive* and *negative* were removed because they are classifications and do not indicate positive or negative emotions; also, emotions (eg, *fear* or *joy*) are indicated by the NRC sentiment lexicon. As a result, a total of eight emotions were evaluated in this analysis. Among the eight emotions, *trust* and *joy* were considered to be positive emotions, while *anger*, *sadness*, *fear*, and *disgust* were considered to be negative emotions. *Surprise* and *anticipation* could be either positive or negative depending on the context.

Finally, topic modeling based on unsupervised machine learning analysis was used to identify the most common topics in the tweets as well as to categorize clusters and find themes based on the keyword analysis. To perform topic modeling, the latent Dirichlet allocation (LDA) algorithm was applied. LDA is an unsupervised document classification method that is similar to clustering on numeric data; it can be used to find natural groups of items even when it is not certain what is being searched. The LDA algorithm is a particularly popular method for fitting a topic model. It treats each document as a mixture of topics and each topic as a mixture of words. In this process, tweeted messages can overlap each other in terms of content rather than be separated into different groups. In this study, we used the “tidy()” method, which is included in the broom package [28]. The “tidytext” package provides a method to extract the per-topic-per-word probabilities, called beta, from the model. To obtain the optimum number of topics, the main target was to compute the topic coherence for different numbers of topics and choose the model that gives the highest topic coherence. Coherence gives the probabilistic coherence of each topic. The coherence score is a score that indicates whether the words in the same topic make sense when they are extracted by those topics. The higher the score for a specific number *k*, the more closely related the words. Word clouds were used to represent topics that were classified based on the 10 most common keywords in each group.

Results

Twitter Trends During the COVID-19 Pandemic

Figure 1 illustrates the retweet frequency of COVID_19-related tweets, showing that the trend line increased from January 7-9 to the first peak (Points A and B). The highest intensity peaks appeared from January 28-29 (Point E), with a second peak from February 9-11 (Point F) and a third peak from February 27-28 (Point G). The fourth peak appeared on March 6 (Point H). These results indicate public awareness, representing the

intensity of conversation activities about COVID-19 on Twitter in the first period from January to its peak at the end of the month. This suggests the existence of an incubation period or early stage (Stage 1) when firsthand data about the severity of the emerging COVID-19 outbreak, including evidence of human-to-human transmission, started to appear. Data compilation of words related to symptoms of COVID-19 infection at the prodromal phase, including *fever*, *dry cough*, and *malaise*, was nonspecific. During the period from January 21-24 (Points C and D), the first confirmed American case of COVID-19 was declared in Seattle, and infection of health care workers was occurring. The spread had become more severe and general by the end of January, when the United States declared a public health emergency (Point E). In that period of time, the Tweet message intensity reached its first major peak.

Thereafter, the worldwide epidemic period began (Stage 2) during which the disease spread globally, negatively impacting health and economic activity. It is now known that during the epidemic period, the outbreak spread from China to other

regions and countries, including Hong Kong, Taiwan, and Macau, as well as to East Asian countries such as Japan and South Korea. During this time, there was discussion on Twitter about the fatality rate, which was as high as 3%, until the panic or peak period at the end of January. The second major peak (Point F) occurred from February 7-9, when WHO officials announced that they had identified a new virus called 2019-nCoV (COVID-19), causing intense activity on Twitter. On February 27, when the third major peak began, COVID-19 reached Europe, and Italy saw a spike in the number of infections, which jumped to 650. It can be said that these two events indicated a worldwide pandemic, as COVID-19 spread from Asia to America and Europe after the first European outbreak in Italy. Later, policies such as social distancing and lockdowns were put in place. This was a stable stage (Stage 3) from the perspective of public awareness. Twitter intensity peaked again on March 6 (Point H), when the number of persons affected by COVID-19 surpassed 100,000. COVID-19 continued to spread even as the WHO urged countries to exert more effort to stop the spread of the disease [29].

Figure 1. Frequency of retweets regarding the COVID-19 pandemic from December 13, 2019, to March 9, 2020. (A) A novel coronavirus was isolated; (B) the first fatal case was reported; (C) the first case of COVID-19 in the United States was confirmed; (D) 835 cases were reported in China; (E) the World Health Organization (WHO) declared a public health emergency of international concern; (F) the WHO announced the name “COVID-19”; (G) infections spiked in Italy and the rest of Europe; (H) the number of COVID-19 cases surpassed 100,000.

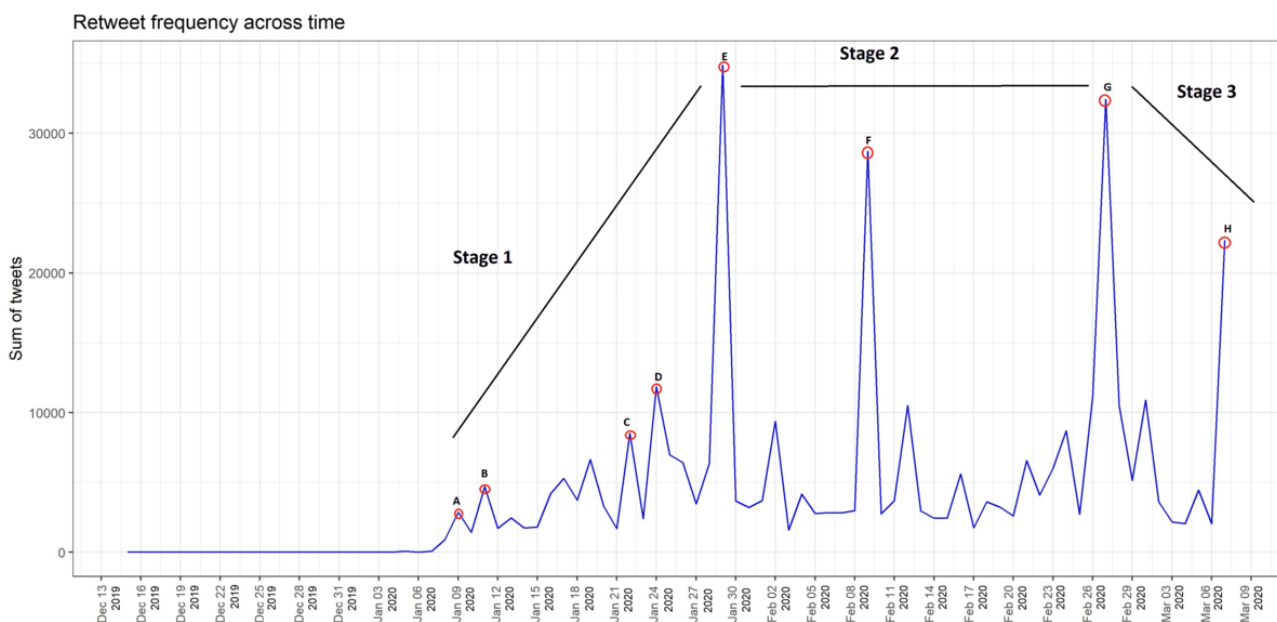
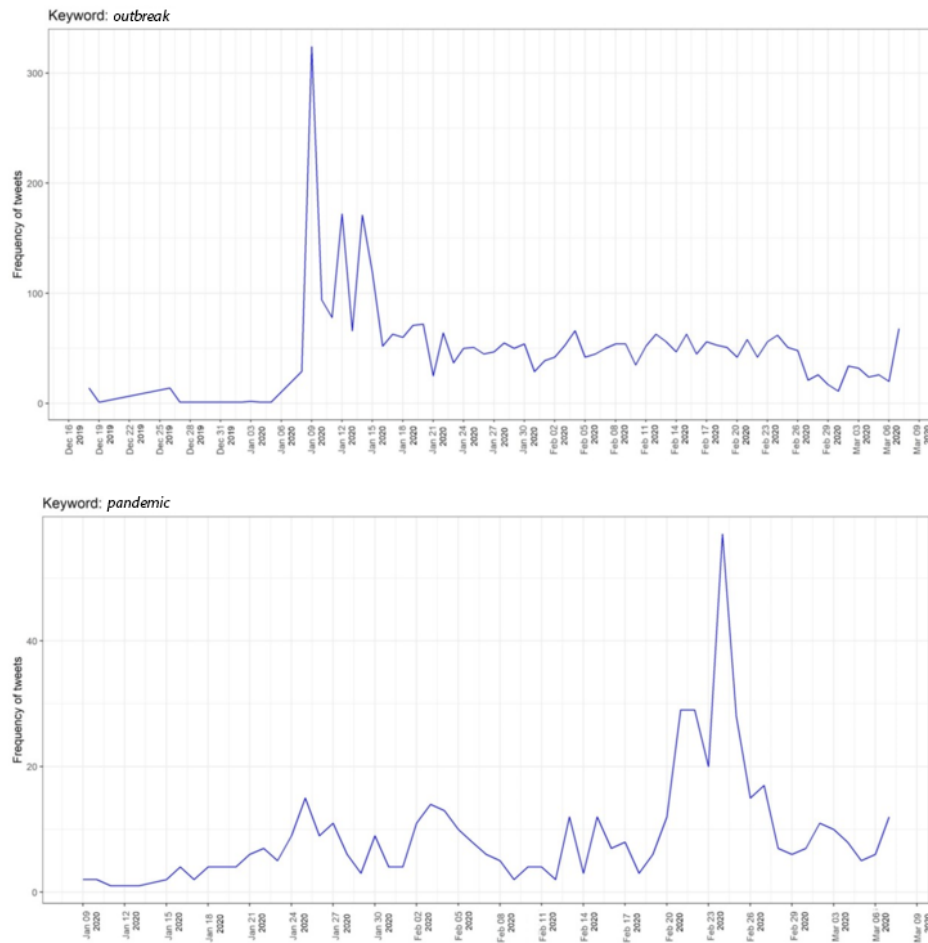


Figure 2 shows the Twitter intensities for two related but distinct keywords: *outbreak* and *pandemic*. The trend line for the keyword *outbreak* peaked between January 9 and 11. As the number of infections increased, Chinese officials stated that they had identified a new virus in the coronavirus family. It was initially named 2019-nCoV, which was later updated to COVID-19. This was the beginning of the outbreak of COVID-19, represented by high numbers of tweets including

the word *outbreak*. Before COVID-19 reached the pandemic level, the trend line for the keyword *pandemic* peaked on February 24 as the virus spread from Asia to other continents. During that time, the WHO announced COVID-19 to be a worldwide epidemic that affected different countries in different ways. The word *pandemic* thus accurately described the situation.

Figure 2. Frequencies of the keywords *outbreak* and *pandemic* on Twitter.



Twitter Trend Lines of COVID-19 Symptoms

Figure 3 shows trend lines indicating the word frequency counts for the key symptoms of COVID-19 on Twitter, which may reflect users’ views and concerns about COVID-19 symptoms. The two key symptoms of COVID-19 are cough and fever [30]; common symptoms also include headaches and sneezing. Other

symptoms (eg, body pain, runny nose, skin rash, frequent urination) are not shown in Figure 3 because only the four key symptoms were used to plot the graph. The word *pneumonia* was removed because this condition describes inflammation of the tissue in one or both lungs; we wished to look at other related symptoms and rank their daily Twitter data mentions to indicate public awareness and trends of COVID-19 symptoms.

Figure 3. Trend lines indicating the word frequencies of four key COVID-19 symptoms on Twitter.

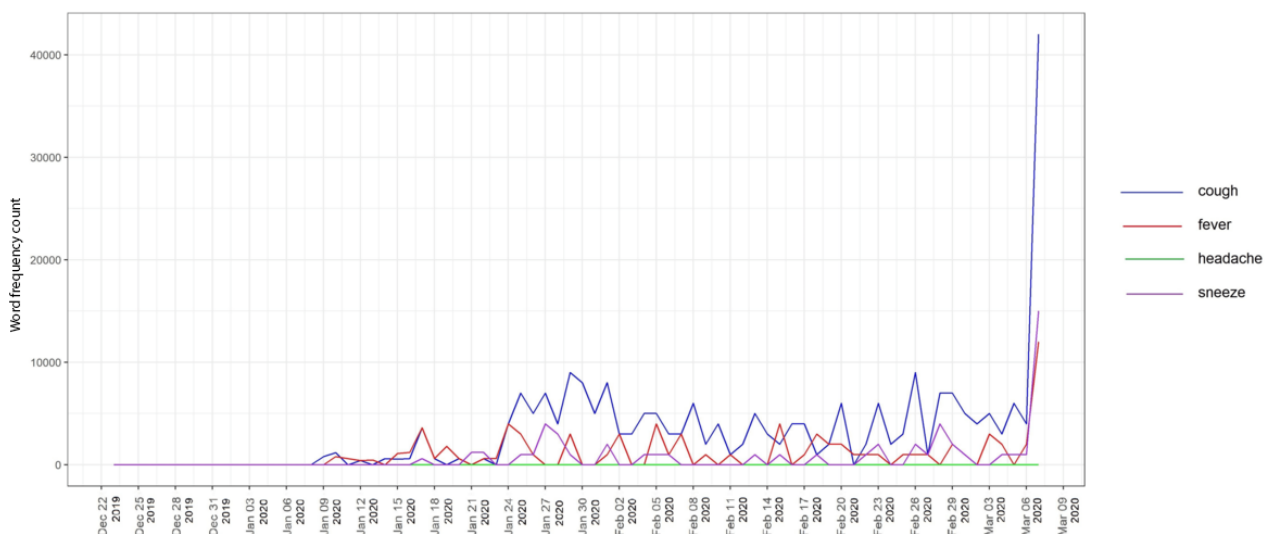
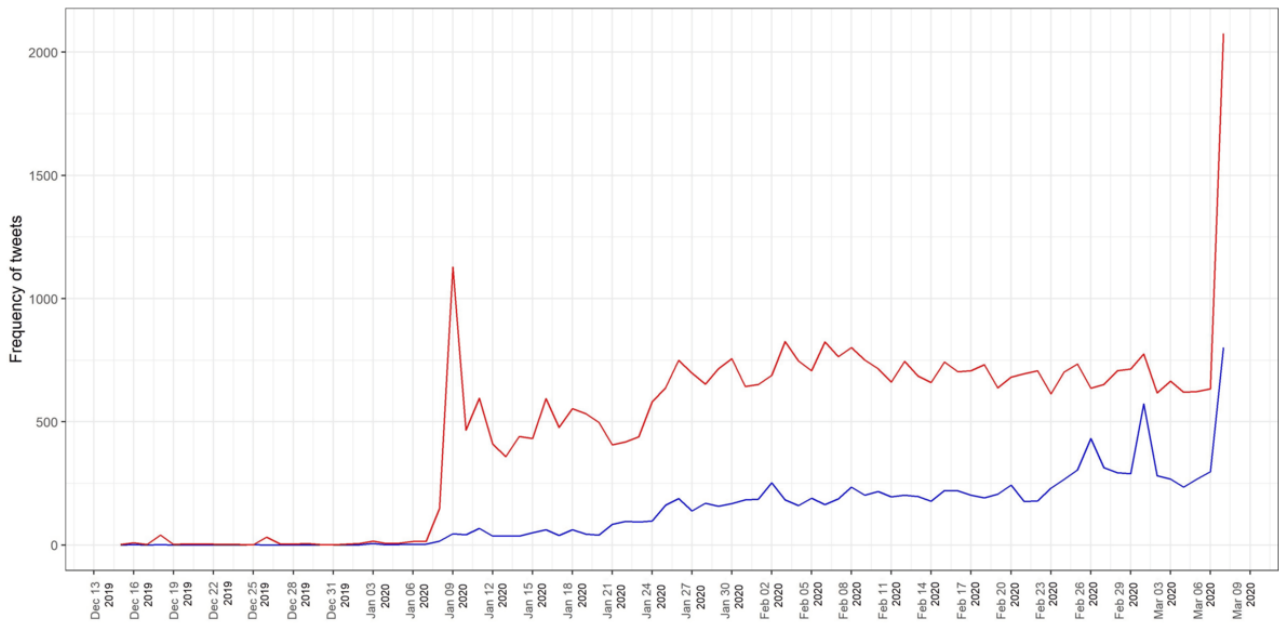


Figure 6. Sentiment analysis of negative (red line) and positive (blue line) tweets related to COVID-19.



The analysis of the emotional quotient of the tweets using the NRC lexicon (Figure 7) found that over half of the tweets posted worldwide were defined by three emotions, namely fear, trust, and anticipation. Figure 8 shows that the tweets expressing the emotion of fear comprised approximately one fifth (21.19%, n=22,883) of the total tweets analyzed. Following the fear emotion was the trust emotion, which indicated that people were looking forward to recovery or to solutions from experts. Similarly, the emotion of anticipation was associated with almost 15.16% (n=16,371) of the tweets, which strengthens the positive

sentiments of the people. Negative emotions, such as sadness, anger, and disgust, were seen in a portion of the tweets, with shares of 13.20% (n=14,254), 10.73% (n=11,588), and 8.86% (n=9,568), respectively. Only a small portion (6.18%, n=6,673) were categorized as joy, which is a positive emotion. These results show that people had a negative outlook toward COVID-19. As shown in Figure 9, the positive sentiment keywords in the tweets were *patient, protect, tough, safe, and cure*, while the keywords expressing negative sentiments were *outbreak, virus, death, infected, and fear*.

Figure 7. Sentiment analysis based on terms in the National Research Council sentiment lexicon.

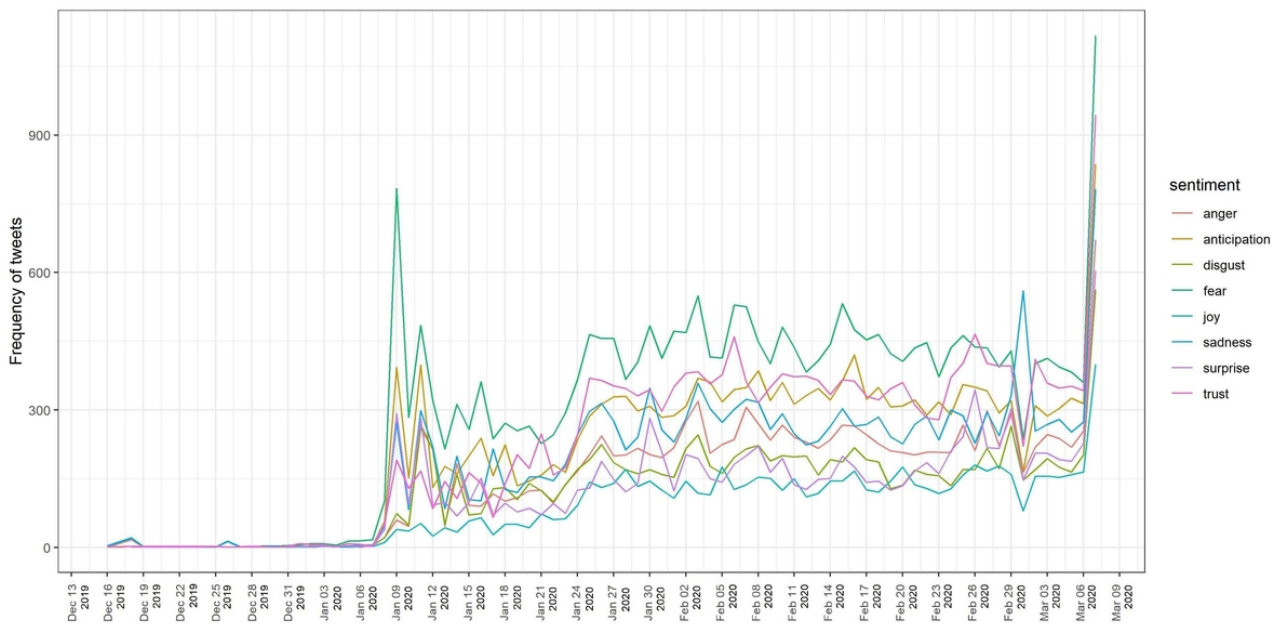


Figure 8. Sentiment wheel showing the emotional quotients of the studied tweets.

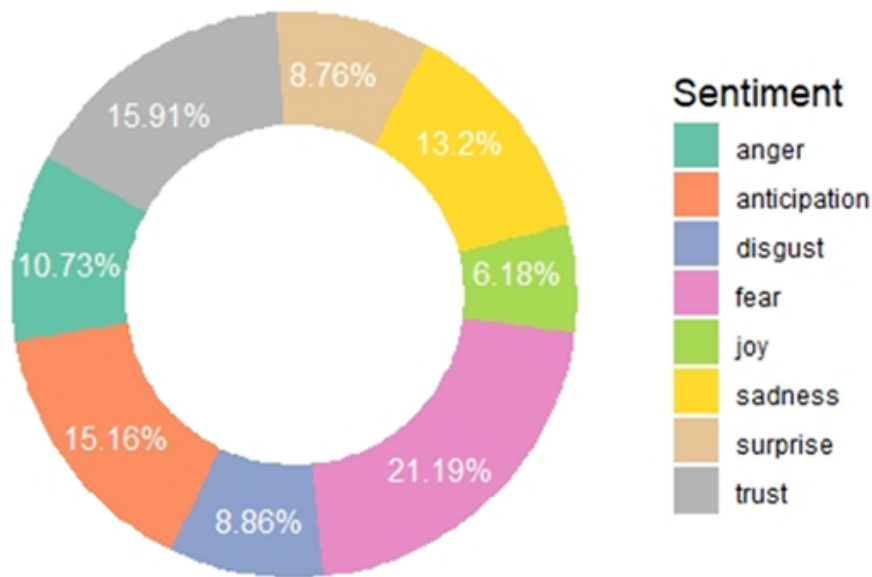
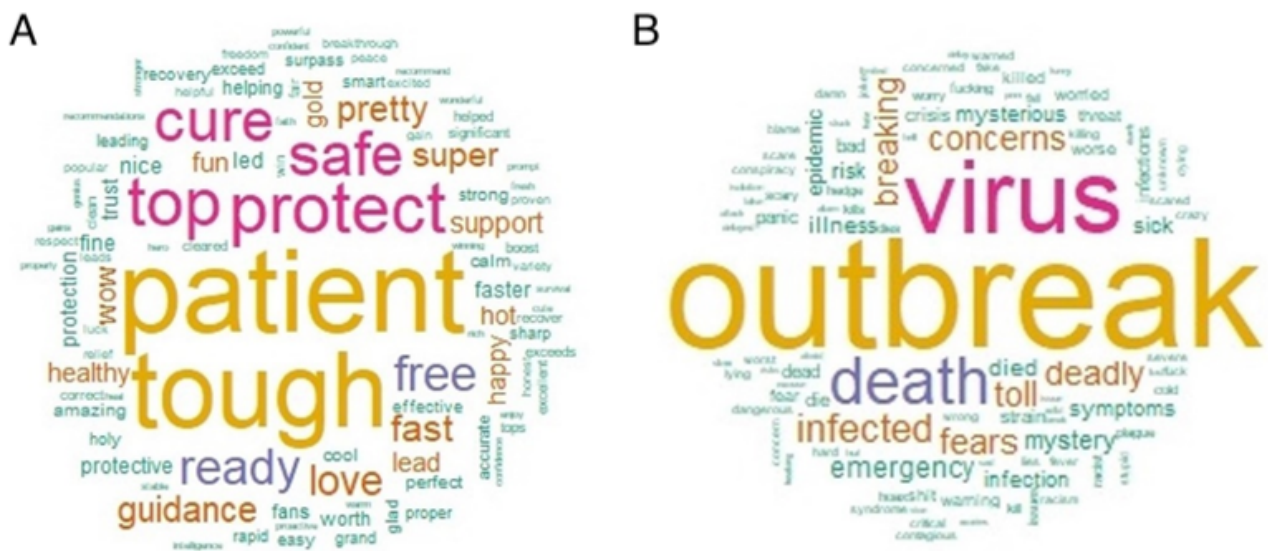
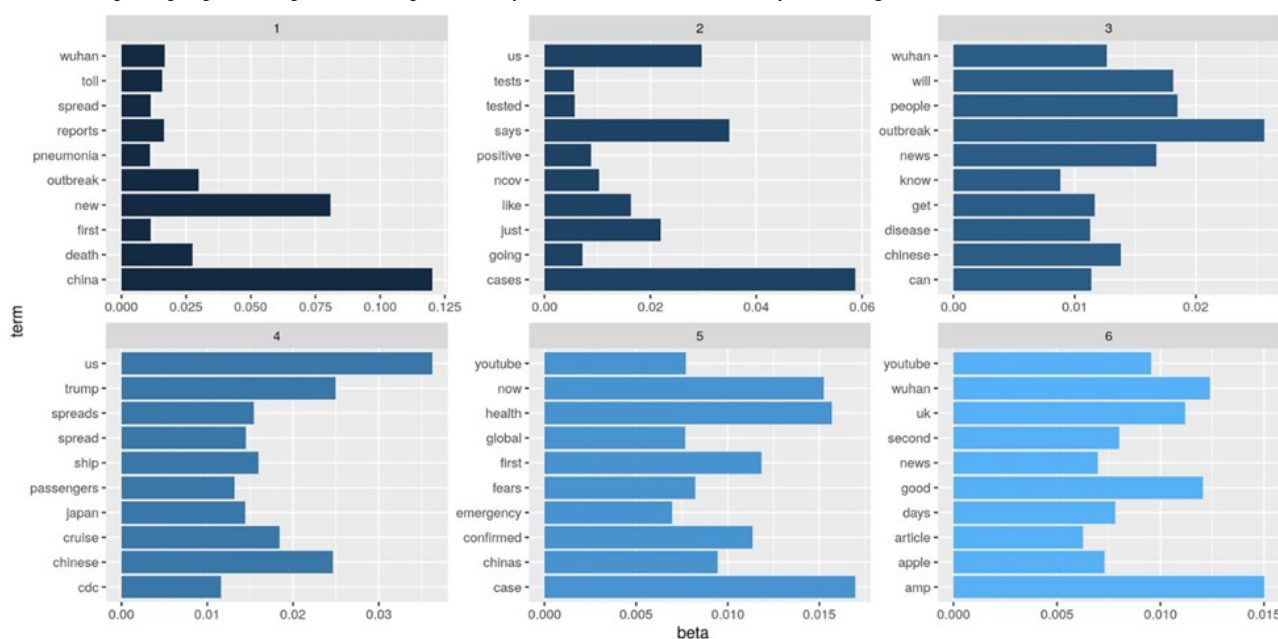


Figure 9. Word clouds of frequent positive (A) and negative (B) keywords related to the COVID-19 epidemic.



For the next phase of the sentiment analysis, a word cloud was created using the most frequently used emotion words, which were categorized by color. The sentiments were part of the sentiment library in R (the textdata package), in which each emotion was separated with no overlap. The word cloud was developed based on the whole corpus of tweets. The results in Figure 10 show that the word *death* was tweeted most frequently in this context. As illustrated in Figure 10, words such as *death*, *mystery* (*mysterious*), *epidemic*, and *guess* were the most frequently used words related with the emotion of surprise.

Words such as *pneumonia*, *flu*, *infection*, *panic*, and *quarantine* were tweeted frequently and were related with the emotion of fear. Words such as *disease*, *deadly*, and *sick* were tweeted frequently with the emotion of disgust. Words such as *pandemic*, *illness*, and *hospital* were frequently tweeted with the emotion of sadness. For the positive sentiments, people tweeted words such as *hope*, *safe*, and *diamond* to express the emotion of joy, while words such as *confirmed*, *doctor*, and *expert* were regularly used with the emotion of trust.

Figure 12. The per-topic-per-word probabilities produced by latent Dirichlet allocation by extracting the beta matrix.

Topic 1 involves discussion related to the report of new cases of deadly pneumonia in China and the outbreak of COVID-19. Examples of keywords include *China*, *death*, *first*, *new*, *outbreak*, *pneumonia*, *reports*, *spread*, *toll*, and *Wuhan*. The word with the highest beta value is *China*. Topic 2 focuses on the epidemic situation and confirmed positive cases of COVID-19. Examples of keywords include *cases*, *going*, *just*, *like*, *nCov*, *positive*, *says*, *tested*, *tests*, and *US*. The words in Topic 3 collectively relate to what people learned from news reports about COVID-19 and the outbreak, with terms such as *outbreak*, *news*, *know*, and *disease*. The top words in Topic 4 describe the spread of COVID-19 and how to control the disease, while those in Topic 5 capture health concerns and fear regarding COVID-19 as an emergency. Some of the top 10 words in these topics are *wear*, *emergency*, and *health*, which are generally believed to be terms related to health concerns. Topic 6 is collectively associated with news and information reports on social media regarding COVID-19. The top terms in Topic 6 are *news*, *articles*, and *YouTube*.

The qualitative content analysis approach enabled the categorization of these topics into different distinct themes. As shown in Table 1, the sample tweets in each topic were categorized and identified according to six topics, which were then assigned to three different themes. The theme identified based on the keywords in Topic 1 and Topic 5 is “the emergency of the COVID-19 pandemic,” which provides information on the reporting of new cases and deaths during the COVID-19 outbreak and health concerns regarding the worldwide emergency. Sample tweets include “Top WHO official warned the world may be ‘dangerously unprepared’ for next pandemic as coronavirus outbreak spreads” and “The US health

department declared the coronavirus a health emergency, 8 cases confirmed in the US, 259 dead over 11K infected in China.”

Topics 2 and 4 reflect the theme of “how to control the COVID-19 pandemic,” relating to the epidemic situation and confirmed cases of COVID-19 and its spread. Sample tweets include “Fox News’ Maria Bartiromo predicted ‘hundreds of thousands of US coronavirus cases: ‘I don’t want to panic anybody’” and “As the coronavirus grows and infects and kills more people, [US president] Trump slashed the budget for the CDC [US Centers for Disease Control and Prevention] that controls disease.” Topics 3 and 6 reflect the final theme of “reports on the COVID-19 pandemic,” which is about the channels receiving news and information about COVID-19; example tweets include “#Coronavirus has been dominating the news, but how much do we need to worry about it” and “China spent the crucial first days of the Wuhan coronavirus outbreak arresting people who posted.”

COVID-19 Outbreak-Related Themes

To explore the keywords for themes reflecting topics related to the COVID-19 outbreak, we used word clouds and topic modeling to generate themes and determine the co-occurrence of topic keywords related specifically to the *outbreak* of COVID-19. The results are shown in Figure 13. The main three issues of public concern regarding the COVID-19 outbreak were the COVID-19 illness, the status of the outbreak in Wuhan, China, and the situation in the news. The high-frequency keywords regarding these issues can be divided into three topics: the new strain of pneumonia identified in Wuhan, China; the mysterious illness caused by the novel virus; and the warning from China that the death toll of COVID-19 could increase.

Discussion

Principal Findings

This Twitter data analysis can be used to explain the public awareness and perception of the COVID-19 pandemic. Based on public awareness, the data were divided into three main stages in relation to the timeline of the epidemic. The early or incubation stage (Stage 1) was the phase in which the severity and the spread of COVID-19 began to increase. The public started to become aware of the severity and rapid spread of the disease and then became afraid, especially when the WHO announced the emergence of a novel and mysterious virus related to pneumonia. This result is in accordance with a previous study [31], which explained the different stages of the public's attention to COVID-19. It is necessary to avoid undermining the possibility of a serious outbreak during the incubation stage [32]. Stage 2 was the worldwide epidemic stage. In Stage 3, the public began to become more aware, as scientific and medical understanding of the disease increased and governments announced the need for social distancing and lockdowns. This was a stable stage from the perspective of public perception, where public awareness tended to be positive.

The mentions of COVID-19 symptoms demonstrated that fever was recognized as the major symptom of COVID-19, which is in accordance with research results stating that fever is seen in 94.3% of cases and is the most common symptom present at the onset of illness (87.1%), followed by coughing (36.5%) and fatigue (15.7%) [33,34]. These common symptoms, including fever and cough, remain consistent across several studies [35]. Fever is understood to be a precursory indicator of COVID-19. After that, the virus progresses to the respiratory system, causing pneumonia and a severe cough [27]. Coughing is a significant symptom in the late stage of fever. However, other symptoms are mentioned, such as a stuffed nose and headache.

The results of the sentiment analysis of tweets related to COVID-19 showed that the most important keyword was *outbreak*, which was related to the starting point of the disease in Wuhan, China. The keywords related to public awareness were different according to the stage of the spread; this includes public emotion, which was mostly more negative than positive, where *fear* was the most negative word [36,37]. In previous disease pandemics, negative sentiments were generally prevalent in social media [38]. A study by Raamkumar [39] showed that *fear* was the most negative sentiment expressed about COVID-19. As the epidemic progressed, however, public sentiment tended to be more positive because additional news was being reported at this stage. The result is in accordance with previous research showing that on social media, people's interests are related to the latest news and major events regarding infectious diseases [40]. Studies have also indicated that people pay attention to and search for disease-related words as the spread of infectious disease changes [41].

The COVID-19 crisis has stimulated great public concern worldwide. Users on Twitter discussed six main topics across three main themes of (1) the emergency of the COVID-19 pandemic, (2) how to control the COVID-19 pandemic, and (3) reports on the COVID-19 pandemic. Previous studies have also

shown that prevention and control procedures, including quarantine, as well as reports on confirmed cases and medical treatments were major themes during previous disease outbreaks [42-45].

Practical Implications

Policy makers should recognize that Twitter data can be used to explore levels of public awareness and emotions about the COVID-19 pandemic. It is important to note that the levels of public awareness are dynamic, which can be observed from the two or three awareness peaks in a period of just a few months in this study. The results also suggest that people express negative emotions and share both information and misinformation via social media platforms during the different stages of the disease. People usually feel great fear during pandemics. The government should synchronize the flow of information and combat "fake news" about the pandemic to diminish this fear. It is also suggested that the government should mitigate the impact of this emotion by implementing countermeasures and building national surveillance systems to examine web-based content, including social media, to better understand the emotions of the public. Misinformation on the internet can create mass panic and result in negative actions. There is a need for a more proactive public health presence on social media. In addition, governments should clearly convey and communicate information regarding COVID-19 to their populations. Key decisions and actions must be informed by accurate and timely data on the delivery and uses of health services throughout all phases of the COVID-19 pandemic.

As COVID-19 continues to spread, more efforts from governments and public health agencies are needed to answer ongoing questions. Twitter users focus on discussing and reacting to health concerns, public health interventions, and controlling the pandemic. This type of information helps governments to understand which public health messages are resonating. For example, how can governments respond in the short term as well as the long term to keep people safe? Governments at all levels need to improve their responses. Governments and public health entities need to ensure that health care systems are prepared to handle increasing numbers of cases. Community-based health care is an essential part of primary care to respond to the COVID-19 pandemic. The recognition of public concern and awareness can help governments understand what the public is thinking about the disease at a particular time. When the results are connected, a valuable health care resource can be established to develop a future plan.

Limitations

This study contains several limitations. First, it is worth mentioning that this study used keywords related to COVID-19 to investigate trends and frequencies of keywords. The list of selected keywords may have been incomplete. The keywords used in this study can be extended to cover the search of tweets by combining keywords related to COVID-19 and its symptoms. Further research could aim to identify the most relevant set of keywords with a high level of detail based on the number of tweets that include symptoms and other keywords. Second, this research was performed in the early phase of the pandemic,

which ultimately spread worldwide. This limited the scope of public awareness of the total picture of the pandemic as well as the pandemic cycle. Thus, a study focusing on public concern after the mentioned period may provide useful results for comparison. Third, although LDA was advantageous in extracting hidden themes, the scientific quality of the themes should be further validated. Furthermore, researchers can play a greater role in extracting themes. Moreover, it is necessary to

reduce bias, which may occur when identifying topic themes using topic modeling. Finally, it may be difficult to identify perfect sources of information on social media because the amount of information regarding COVID-19 is overwhelming. This research collected data from Twitter only; further research should use other resources such as mass media or other data sources in addition to social media information.

Conflicts of Interest

None declared.

References

1. Kilbourne ED. Influenza pandemics of the 20th century. *Emerg Infect Dis* 2006 Jan;12(1):9-14 [FREE Full text] [doi: [10.3201/eid1201.051254](https://doi.org/10.3201/eid1201.051254)] [Medline: [16494710](https://pubmed.ncbi.nlm.nih.gov/16494710/)]
2. Ather A, Patel B, Ruparel NB, Diogenes A, Hargreaves KM. Coronavirus Disease 19 (COVID-19): Implications for Clinical Dental Care. *J Endod* 2020 May;46(5):584-595 [FREE Full text] [doi: [10.1016/j.joen.2020.03.008](https://doi.org/10.1016/j.joen.2020.03.008)] [Medline: [32273156](https://pubmed.ncbi.nlm.nih.gov/32273156/)]
3. Coronavirus disease (COVID-19) pandemic. World Health Organization. URL: <https://www.who.int/emergencies/diseases/novel-coronavirus-2019> [accessed 2020-04-15]
4. Adhikari SP, Meng S, Wu Y, Mao Y, Ye R, Wang Q, et al. Epidemiology, causes, clinical manifestation and diagnosis, prevention and control of coronavirus disease (COVID-19) during the early outbreak period: a scoping review. *Infect Dis Poverty* 2020 Mar 17;9(1):29 [FREE Full text] [doi: [10.1186/s40249-020-00646-x](https://doi.org/10.1186/s40249-020-00646-x)] [Medline: [32183901](https://pubmed.ncbi.nlm.nih.gov/32183901/)]
5. Ginsberg J, Mohebbi MH, Patel RS, Brammer L, Smolinski MS, Brilliant L. Detecting influenza epidemics using search engine query data. *Nature* 2009 Mar 19;457(7232):1012-1014. [doi: [10.1038/nature07634](https://doi.org/10.1038/nature07634)] [Medline: [19020500](https://pubmed.ncbi.nlm.nih.gov/19020500/)]
6. Jahanbin K, Rahmanian V. Using Twitter and web news mining to predict COVID-19 outbreak. *Asian Pac J of Trop Med* 2020; 13(8):378-380 [FREE Full text]
7. Charles-Smith LE, Reynolds TL, Cameron MA, Conway M, Lau EHY, Olsen JM, et al. Using Social Media for Actionable Disease Surveillance and Outbreak Management: A Systematic Literature Review. *PLoS One* 2015 Oct 5;10(10):e0139701 [FREE Full text] [doi: [10.1371/journal.pone.0139701](https://doi.org/10.1371/journal.pone.0139701)] [Medline: [26437454](https://pubmed.ncbi.nlm.nih.gov/26437454/)]
8. Chew C, Eysenbach G. Pandemics in the age of Twitter: content analysis of Tweets during the 2009 H1N1 outbreak. *PLoS One* 2010 Nov 29;5(11):e14118 [FREE Full text] [doi: [10.1371/journal.pone.0014118](https://doi.org/10.1371/journal.pone.0014118)] [Medline: [21124761](https://pubmed.ncbi.nlm.nih.gov/21124761/)]
9. Werron T, Ringel L. Pandemic Practices, Part One: How to Turn “Living Through the COVID-19 Pandemic” into a Heuristic Tool for Sociological Theorizing. *Sociologica* 2020;14(2):55-72. [doi: [10.6092/issn.1971-8853/11172](https://doi.org/10.6092/issn.1971-8853/11172)]
10. Li S, Wang Y, Xue J, Zhao N, Zhu T. The Impact of COVID-19 Epidemic Declaration on Psychological Consequences: A Study on Active Weibo Users. *Int J Environ Res Public Health* 2020 Mar 19;17(6):2032 [FREE Full text] [doi: [10.3390/ijerph17062032](https://doi.org/10.3390/ijerph17062032)] [Medline: [32204411](https://pubmed.ncbi.nlm.nih.gov/32204411/)]
11. Bartlett C, Wurtz R. Twitter and Public Health. *J Public Health Manag Pract* 2015;21(4):375-383. [doi: [10.1097/phh.0000000000000041](https://doi.org/10.1097/phh.0000000000000041)]
12. Shen C, Chen A, Luo C, Zhang J, Feng B, Liao W. Using Reports of Symptoms and Diagnoses on Social Media to Predict COVID-19 Case Counts in Mainland China: Observational Infoveillance Study. *J Med Internet Res* 2020 May 28;22(5):e19421 [FREE Full text] [doi: [10.2196/19421](https://doi.org/10.2196/19421)] [Medline: [32452804](https://pubmed.ncbi.nlm.nih.gov/32452804/)]
13. Huang C, Xu X, Cai Y, Ge Q, Zeng G, Li X, et al. Mining the Characteristics of COVID-19 Patients in China: Analysis of Social Media Posts. *J Med Internet Res* 2020 May 17;22(5):e19087 [FREE Full text] [doi: [10.2196/19087](https://doi.org/10.2196/19087)] [Medline: [32401210](https://pubmed.ncbi.nlm.nih.gov/32401210/)]
14. Park HW, Park S, Chong M. Conversations and Medical News Frames on Twitter: Infodemiological Study on COVID-19 in South Korea. *J Med Internet Res* 2020 May 05;22(5):e18897 [FREE Full text] [doi: [10.2196/18897](https://doi.org/10.2196/18897)] [Medline: [32325426](https://pubmed.ncbi.nlm.nih.gov/32325426/)]
15. Abd-Alrazaq A, Alhuwail D, Househ M, Hamdi M, Shah Z. Top Concerns of Tweeters During the COVID-19 Pandemic: Infoveillance Study. *J Med Internet Res* 2020 Apr 21;22(4):e19016 [FREE Full text] [doi: [10.2196/19016](https://doi.org/10.2196/19016)] [Medline: [32287039](https://pubmed.ncbi.nlm.nih.gov/32287039/)]
16. Chen E, Lerman K, Ferrara E. Tracking Social Media Discourse About the COVID-19 Pandemic: Development of a Public Coronavirus Twitter Data Set. *JMIR Public Health Surveill* 2020 May 29;6(2):e19273 [FREE Full text] [doi: [10.2196/19273](https://doi.org/10.2196/19273)] [Medline: [32427106](https://pubmed.ncbi.nlm.nih.gov/32427106/)]
17. Lwin M, Lu J, Sheldenkar A, Schulz P, Shin W, Gupta R, et al. Global Sentiments Surrounding the COVID-19 Pandemic on Twitter: Analysis of Twitter Trends. *JMIR Public Health Surveill* 2020 May 22;6(2):e19447 [FREE Full text] [doi: [10.2196/19447](https://doi.org/10.2196/19447)] [Medline: [32412418](https://pubmed.ncbi.nlm.nih.gov/32412418/)]
18. Samuel J, Ali G, Rahman M, Esawi E, Samuel Y. COVID-19 Public Sentiment Insights and Machine Learning for Tweets Classification. *Information* 2020 Jun 11;11(6):314. [doi: [10.3390/info11060314](https://doi.org/10.3390/info11060314)]

19. Dai H, Deem MJ, Hao J. Geographic variations in electronic cigarette advertisements on Twitter in the United States. *Int J Public Health* 2017 May;62(4):479-487. [doi: [10.1007/s00038-016-0906-9](https://doi.org/10.1007/s00038-016-0906-9)] [Medline: [27742923](https://pubmed.ncbi.nlm.nih.gov/27742923/)]
20. Nair MR, Ramya G, Sivakumar PB. Usage and analysis of Twitter during 2015 Chennai flood towards disaster management. *Procedia Comp Sci* 2017;115:350-358. [doi: [10.1016/j.procs.2017.09.089](https://doi.org/10.1016/j.procs.2017.09.089)]
21. Fu K, Liang H, Saroha N, Tse ZTH, Ip P, Fung IC. How people react to Zika virus outbreaks on Twitter? A computational content analysis. *Am J Infect Control* 2016 Dec 01;44(12):1700-1702. [doi: [10.1016/j.ajic.2016.04.253](https://doi.org/10.1016/j.ajic.2016.04.253)] [Medline: [27566874](https://pubmed.ncbi.nlm.nih.gov/27566874/)]
22. searchtweets 1.7.6. pypi.org. URL: <https://pypi.org/project/searchtweets/> [accessed 2020-10-30]
23. Shi Z, Rui H, Whinston AB. Content Sharing in a Social Broadcasting Environment: Evidence from Twitter. *MISQ* 2014 Jan 1;38(1):123-142. [doi: [10.25300/MISQ/2014/38.1.06](https://doi.org/10.25300/MISQ/2014/38.1.06)]
24. Panda M. Developing an Efficient Text Pre-Processing Method with Sparse Generative Naive Bayes for Text Mining. *IJMECS* 2018 Sep 08;10(9):11-19. [doi: [10.5815/ijmeecs.2018.09.02](https://doi.org/10.5815/ijmeecs.2018.09.02)]
25. Guo X, Li J. A Novel Twitter Sentiment Analysis Model with Baseline Correlation for Financial Market Prediction with Improved Efficiency. 2019 Presented at: Sixth International Conference on Social Networks Analysis, Management and Security (SNAMS); October 22-25, 2019; Granada, Spain p. 472-477. [doi: [10.1109/snams.2019.8931720](https://doi.org/10.1109/snams.2019.8931720)]
26. Sarker A, Lakamana S, Hogg-Bremer W, Xie A, Al-Garadi M, Yang Y. Self-reported COVID-19 symptoms on Twitter: an analysis and a research resource. *J Am Med Inform Assoc* 2020 Aug 01;27(8):1310-1315 [FREE Full text] [doi: [10.1093/jamia/ocaa116](https://doi.org/10.1093/jamia/ocaa116)] [Medline: [32620975](https://pubmed.ncbi.nlm.nih.gov/32620975/)]
27. Murray C, Mitchell L, Tuke J, Mackay M. Symptom extraction from the narratives of personal experiences with COVID-19 on Reddit. ArXiv Preprint posted online on May 21, 2020.
28. Lüdecke D, Ben-Shachar M, Patil I, Makowski D. Extracting, Computing and Exploring the Parameters of Statistical Models using R. *JOSS* 2020 Sep;5(53):2445. [doi: [10.21105/joss.02445](https://doi.org/10.21105/joss.02445)]
29. Nebehay S, Kelland K. WHO urges countries to make containing coronavirus 'highest priority'. Reuters. 2020 Mar 06. URL: <https://ca.reuters.com/article/idUSKBN20T2BH> [accessed 2020-10-30]
30. Geldsetzer P. Use of Rapid Online Surveys to Assess People's Perceptions During Infectious Disease Outbreaks: A Cross-sectional Survey on COVID-19. *J Med Internet Res* 2020 Apr 02;22(4):e18790 [FREE Full text] [doi: [10.2196/18790](https://doi.org/10.2196/18790)] [Medline: [32240094](https://pubmed.ncbi.nlm.nih.gov/32240094/)]
31. Zhao Y, Cheng S, Yu X, Xu H. Chinese Public's Attention to the COVID-19 Epidemic on Social Media: Observational Descriptive Study. *J Med Internet Res* 2020 May 04;22(5):e18825 [FREE Full text] [doi: [10.2196/18825](https://doi.org/10.2196/18825)] [Medline: [32314976](https://pubmed.ncbi.nlm.nih.gov/32314976/)]
32. Lwin M, Lu J, Sheldenkar A, Schulz P. Strategic Uses of Facebook in Zika Outbreak Communication: Implications for the Crisis and Emergency Risk Communication Model. *Int J Environ Res Public Health* 2018 Sep 10;15(9). [doi: [10.3390/ijerph15091974](https://doi.org/10.3390/ijerph15091974)] [Medline: [30201929](https://pubmed.ncbi.nlm.nih.gov/30201929/)]
33. Chen J, Qi T, Liu L, Ling Y, Qian Z, Li T, et al. Clinical progression of patients with COVID-19 in Shanghai, China. *J Infect* 2020 May;80(5):e1-e6 [FREE Full text] [doi: [10.1016/j.jinf.2020.03.004](https://doi.org/10.1016/j.jinf.2020.03.004)] [Medline: [32171869](https://pubmed.ncbi.nlm.nih.gov/32171869/)]
34. Huang C, Xu X, Cai Y, Ge Q, Zeng G, Li X, et al. Mining the Characteristics of COVID-19 Patients in China: Analysis of Social Media Posts. *J Med Internet Res* 2020 May 17;22(5):e19087 [FREE Full text] [doi: [10.2196/19087](https://doi.org/10.2196/19087)] [Medline: [32401210](https://pubmed.ncbi.nlm.nih.gov/32401210/)]
35. Rothan HA, Byrareddy SN. The epidemiology and pathogenesis of coronavirus disease (COVID-19) outbreak. *J Autoimmun* 2020 May;109:102433 [FREE Full text] [doi: [10.1016/j.jaut.2020.102433](https://doi.org/10.1016/j.jaut.2020.102433)] [Medline: [32113704](https://pubmed.ncbi.nlm.nih.gov/32113704/)]
36. Dubey AD, Tripathi S. Analysing the Sentiments towards Work-From-Home Experience during COVID-19 Pandemic. *J Innov Manag* 2020 Apr 28;8(1). [doi: [10.24840/2183-0606_008.001_0003](https://doi.org/10.24840/2183-0606_008.001_0003)]
37. Kleinberg B, van der Vegt I, Mozes M. Measuring emotions in the COVID-19 real world worry dataset. ArXiv Preprint posted online on May 14, 2020.
38. Mamidi R, Miller M, Banerjee T, Romine W, Sheth A. Identifying Key Topics Bearing Negative Sentiment on Twitter: Insights Concerning the 2015-2016 Zika Epidemic. *JMIR Public Health Surveill* 2019 Jun 04;5(2):e11036 [FREE Full text] [doi: [10.2196/11036](https://doi.org/10.2196/11036)] [Medline: [31165711](https://pubmed.ncbi.nlm.nih.gov/31165711/)]
39. Sesagiri Raamkumar A, Tan S, Wee H. Measuring the Outreach Efforts of Public Health Authorities and the Public Response on Facebook During the COVID-19 Pandemic in Early 2020: Cross-Country Comparison. *J Med Internet Res* 2020 May 19;22(5):e19334 [FREE Full text] [doi: [10.2196/19334](https://doi.org/10.2196/19334)] [Medline: [32401219](https://pubmed.ncbi.nlm.nih.gov/32401219/)]
40. Southwell BG, Dolina S, Jimenez-Magdaleno K, Squiers LB, Kelly BJ. Zika Virus-Related News Coverage and Online Behavior, United States, Guatemala, and Brazil. *Emerg Infect Dis* 2016 Jul;22(7):1320-1321 [FREE Full text] [doi: [10.3201/eid2207.160415](https://doi.org/10.3201/eid2207.160415)] [Medline: [27100826](https://pubmed.ncbi.nlm.nih.gov/27100826/)]
41. Li L, Zhang Q, Wang X, Zhang J, Wang T, Gao T, et al. Characterizing the Propagation of Situational Information in Social Media During COVID-19 Epidemic: A Case Study on Weibo. *IEEE Trans Comput Soc Syst* 2020 Apr;7(2):556-562. [doi: [10.1109/tcss.2020.2980007](https://doi.org/10.1109/tcss.2020.2980007)]
42. Nussbaumer-Streit B, Mayr V, Dobrescu A, Chapman A, Persad E, Klerings I, et al. Quarantine alone or in combination with other public health measures to control COVID-19: a rapid review. *Cochrane Database Syst Rev* 2020 Apr 08;4:CD013574. [doi: [10.1002/14651858.CD013574](https://doi.org/10.1002/14651858.CD013574)] [Medline: [32267544](https://pubmed.ncbi.nlm.nih.gov/32267544/)]

43. Wilder-Smith A, Chiew CJ, Lee VJ. Can we contain the COVID-19 outbreak with the same measures as for SARS? The Lancet Infectious Diseases 2020 May;20(5):e102-e107. [doi: [10.1016/s1473-3099\(20\)30129-8](https://doi.org/10.1016/s1473-3099(20)30129-8)]
44. Liu Q, Zheng Z, Zheng J, Chen Q, Liu G, Chen S, et al. Health Communication Through News Media During the Early Stage of the COVID-19 Outbreak in China: Digital Topic Modeling Approach. J Med Internet Res 2020 Apr 28;22(4):e19118 [FREE Full text] [doi: [10.2196/19118](https://doi.org/10.2196/19118)] [Medline: [32302966](https://pubmed.ncbi.nlm.nih.gov/32302966/)]
45. Shah K, Kamrai D, Mekala H, Mann B, Desai K, Patel R. Focus on Mental Health During the Coronavirus (COVID-19) Pandemic: Applying Learnings from the Past Outbreaks. Cureus 2020 Mar 25;12(3):e7405 [FREE Full text] [doi: [10.7759/cureus.7405](https://doi.org/10.7759/cureus.7405)] [Medline: [32337131](https://pubmed.ncbi.nlm.nih.gov/32337131/)]

Abbreviations

API: application programming interface
LDA: latent Dirichlet allocation
NLP: natural language processing
NRC: National Research Council
TF-IDF: term frequency-inverse document frequency
WHO: World Health Organization

Edited by G Eysenbach; submitted 30.06.20; peer-reviewed by JP Allem, Q Li, A Alasmari, J Li, T Ndabu, M Adly, A Adly; comments to author 22.07.20; revised version received 11.08.20; accepted 25.10.20; published 11.11.20.

Please cite as:

Boon-Itt S, Skunkan Y

Public Perception of the COVID-19 Pandemic on Twitter: Sentiment Analysis and Topic Modeling Study

JMIR Public Health Surveill 2020;6(4):e21978

URL: <http://publichealth.jmir.org/2020/4/e21978/>

doi: [10.2196/21978](https://doi.org/10.2196/21978)

PMID: [33108310](https://pubmed.ncbi.nlm.nih.gov/33108310/)

©Sakun Boon-Itt, Yukolpat Skunkan. Originally published in JMIR Public Health and Surveillance (<http://publichealth.jmir.org>), 11.11.2020. This is an open-access article distributed under the terms of the Creative Commons Attribution License (<https://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in JMIR Public Health and Surveillance, is properly cited. The complete bibliographic information, a link to the original publication on <http://publichealth.jmir.org>, as well as this copyright and license information must be included.

Original Paper

Analysis of the COVID-19 Epidemic Transmission Network in Mainland China: K-Core Decomposition Study

Lei Qin^{1*}, PhD; Yidan Wang¹, MA; Qiang Sun¹, MA; Xiaomei Zhang¹, MA; Ben-Chang Shia^{2*}, PhD; Chengcheng Liu³, PhD

¹School of Statistics, University of International Business and Economics, Beijing, China

²Graduate Institute of Business Administration, College of Management, Fu Jen Catholic University, New Taipei City, Taiwan

³School of Statistics, Capital University of Economics and Business, Beijing, China

*these authors contributed equally

Corresponding Author:

Chengcheng Liu, PhD

School of Statistics

Capital University of Economics and Business

No 121 Huaxiang Zhangjia Road, Fengtai District

Beijing, 100070

China

Phone: 86 188 1152 1258

Email: ccliu@cueb.edu.cn

Abstract

Background: Since the outbreak of COVID-19 in December 2019 in Wuhan, Hubei Province, China, frequent interregional contacts and the high rate of infection spread have catalyzed the formation of an epidemic network.

Objective: The aim of this study was to identify influential nodes and highlight the hidden structural properties of the COVID-19 epidemic network, which we believe is central to prevention and control of the epidemic.

Methods: We first constructed a network of the COVID-19 epidemic among 31 provinces in mainland China; after some basic characteristics were revealed by the degree distribution, the k-core decomposition method was employed to provide static and dynamic evidence to determine the influential nodes and hierarchical structure. We then exhibited the influence power of the above nodes and the evolution of this power.

Results: Only a small fraction of the provinces studied showed relatively strong outward or inward epidemic transmission effects. The three provinces of Hubei, Beijing, and Guangzhou showed the highest out-degrees, and the three highest in-degrees were observed for the provinces of Beijing, Henan, and Liaoning. In terms of the hierarchical structure of the COVID-19 epidemic network over the whole period, more than half of the 31 provinces were located in the innermost core. Considering the correlation of the characteristics and coreness of each province, we identified some significant negative and positive factors. Specific to the dynamic transmission process of the COVID-19 epidemic, three provinces of Anhui, Beijing, and Guangdong always showed the highest coreness from the third to the sixth week; meanwhile, Hubei Province maintained the highest coreness until the fifth week and then suddenly dropped to the lowest in the sixth week. We also found that the out-strengths of the innermost nodes were greater than their in-strengths before January 27, 2020, at which point a reversal occurred.

Conclusions: Increasing our understanding of how epidemic networks form and function may help reduce the damaging effects of COVID-19 in China as well as in other countries and territories worldwide.

(*JMIR Public Health Surveill* 2020;6(4):e24291) doi:[10.2196/24291](https://doi.org/10.2196/24291)

KEYWORDS

COVID-19; epidemic network; prevention and control; k-core decomposition

Introduction

In December 2019, several cases of pneumonia of unknown etiology were detected in Wuhan City, Hubei Province, China.

Chinese authorities identified the causative agent as a novel coronavirus of probable bat origin [1], and the World Health Organization (WHO) officially named the disease COVID-19 on February 11, 2020 [2]. Compared with the outbreak of severe

acute respiratory syndrome (SARS) in China in 2003, COVID-19 has spread faster and infected more people [3]; furthermore, it is more difficult to prevent and control. Considering that the number of cases started increasing exponentially, the Chinese government imposed a lockdown in Wuhan on January 23, 2020, aiming to cut off the route of virus transmission through a traffic blockade [4]. After that, COVID-19 was clearly brought under control. Since March 2020, this ongoing epidemic has now spread to more than 200 countries and territories, and it is undoubtedly casting a shadow over the global economy. To mitigate the impact of epidemics and ensure the continuity of global social development, an exploration of the influential nodes and structural properties of the COVID-19 epidemic network is urgently needed.

There have been extensive studies on epidemiological transmission mechanisms from diverse perspectives, such as epidemiology, medical statistics, spatial information science, sociology, and dynamic models [5-10]. Due to the wide spread, epidemic data are often presented in the form of a network. The application advantages of complex network theory are gradually being highlighted [11,12]. In the framework of complex network theory, k-core decomposition is usually considered for identifying influential spreaders [13,14] and finding specific structural information [15-18].

K-core decomposition is a well-established method for analyzing the structures of large-scale graphs [19,20]. The original idea of k-core decomposition can be traced back to the concepts of coloring number [21] and degeneracy [22], and the commonly accepted concept was first proposed by Seidman [19]. Further studies mainly involved two aspects. One focuses on solving the theoretical problem of the k-core pruning process in different networks, and the other involves finding the densest part of the network by k-core decomposition across a broad range of scientific subjects, including biology, ecology, computer science, social networks, information spreading, and community detection.

In particular, k-core decomposition provides a method for identifying hierarchies in a network. It considers the coreness of nodes by dividing networks into layers or shells. Compared with other methods, k-core decomposition possesses a significant advantage of computational simplicity [23]. It has found a number of applications as a means to understand the importance of nodes within large-scale network structures [20].

While the existing literature is replete with explorations of epidemic networks and applications of k-core decomposition, few studies involve the effective combination of the two. In the context of the COVID-19 epidemic in mainland China, this paper applies k-core decomposition to the structural analysis of the network of the epidemic with the purpose of arriving at some novel conclusions to aid the prevention and control of the disease. Our contribution is threefold. First, the COVID-19 epidemic data of all provinces in mainland China are timely and unique. Second, we obtained the related static and dynamic conclusions of influential nodes and the hierarchical structure by applying k-core decomposition to the COVID-19 epidemic network; furthermore, we detected the common characteristics of provinces represented by these important nodes. Finally, the

influence power of k-shell nodes and the evolution of this power, measured by out-strength and in-strength, can promote our understanding of the roles of the provinces in epidemic transmission.

In this paper, we briefly introduce the construction and further analytical methods of the COVID-19 epidemic network after describing the data used. We then summarize some basic structural properties of the epidemic network by means of degree distribution. Then, k-core decomposition is applied to the constructed whole period and daily networks to statically and dynamically investigate the network structure. Finally, the influence power (outgoing and incoming) of the k-shell and its evolution are exhibited.

Methods

Data

In view of the construction of COVID-19 epidemic network among the provinces in mainland China, the cross-provincial traveling data (1690 observations) of confirmed patients were considered. In our study, the traveling extent mainly focused on 31 provinces (all except Taiwan, Hong Kong, and Macao) in China, and the traveling options were restricted to air and train travel. The aforementioned data were obtained from a website [24], that includes records from confirmed official WeChat and Weibo accounts as well as official websites. In addition, some unverifiable data were eliminated. In total, 1615 observations (328 observations by plane and 1287 observations by train) were retained, and the period of the observations ranged from December 27, 2019, to February 25, 2020, covering 61 days. It should be noted that a connection between province A and province B can be established in the COVID-19 epidemic network if the traveling data show that a latent confirmed patient traveled from province A to province B and was diagnosed in province B.

Some variables at the provincial level, such as gross domestic product (GDP) per capita, population, volume of passenger transport, starting date of first-level response to the major public health emergency, response time, and distance from Hubei Province were also used in the follow-up study on the common characteristics of provinces represented by important nodes. Specifically, the GDP, population, volume of passenger transport, and starting date of first-level response to the major public health emergency were obtained from the National Bureau of Statistics and Provincial Health Committees. Response time was calculated by the average number of days between the arrival date and the confirmed date, and for the spatial distances from Hubei Province, we referred to Yu [25].

Methodology

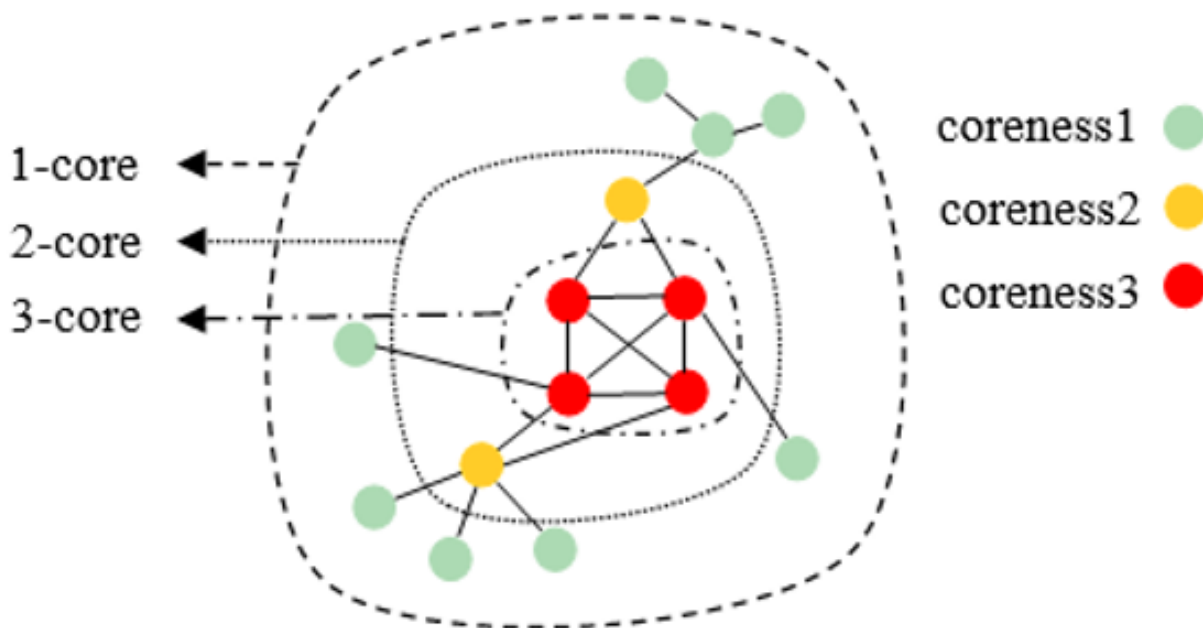
Considering that the causative agent of COVID-19 is carried by humans—in other words, it is mainly spread by human-to-human transmission—the cross-provincial traveling records of confirmed patients can directly depict the epidemic network to a large extent. Specific to the COVID-19 epidemic network $G = (V, E)$, province A and province B can be viewed as node V_A and node V_B , respectively; there are corresponding directional edges E_{AB} or E_{BA} between nodes V_A and V_B if a

confirmed patient traveled from province A to province B or from province B to province A. On this basis, the directionality information of edges was well considered in the following analyses of degree distribution and influence power, but was not considered in the k-core decomposition.

As mentioned before, three methods were applied to the further structural analysis of the COVID-19 epidemic network: degree distribution, k-core decomposition, and influence power. Under the method framework of degree distribution, the degree of a node is defined as its number of connected edges, and it can be divided into an out-degree and in-degree according to the direction of the edges. In addition, the cumulative degree distribution represents the probability distribution of nodes with degree not less than k . In the Degree Distribution section, we will show the cumulative distributions of both the out-degrees and in-degrees to reveal some basic characteristics of the epidemic network. The degree distribution provides useful information about the network; however, it is limited by the revelation of the complete structure. Therefore, other network methods should be applied, such as k-core decomposition.

The advantage of k-core decomposition is that it can be used to detect the core and surrounding shell of a complex network. The fundamental application of this method is to decompose the network into multiple partitions, which is a straightforward procedure. Let $G=(V,E)$ be a graph with $n = |V|$ nodes and $e = |E|$ edges. The so-called k-core is a maximal connected subgraph of G in which the degree of all nodes is at least k . A node V_i has coreness $ks(V_i)=k$ if it belongs to the k-core instead of the $(k+1)$ -core. We note that the value of k is automatically learned from the observed network data and is also independent of our prior anticipation. More specifically, the k-core decomposition method can realize the k-shell classification of all nodes of G by removing them iteratively, as follows. First, we removed all nodes with degree $k=1$ and assigned the coreness value $ks=1$ to the removed nodes. Second, a pruning process was repeated until only nodes with degree $k>1$ remained. Next, we performed a similar pruning process for the nodes with degree $k=2$ and assigned the corresponding coreness value $ks=2$. The above procedures were repeated until all nodes of G were removed and assigned to one of the k-shells. Figure 1 illustrates the simple k-core decomposition of a connected graph.

Figure 1. Illustration of the k-core decomposition of a small network. The sets of nodes belonging to the 1-core, 2-core, and 3-core are enclosed by different types of lines. The different k-shells can also be distinguished by the colors of the nodes.



To identify the important nodes of the COVID-19 epidemic network and reveal its hierarchical structure through k-core decomposition, a geospatial network topology map of the whole time period showing the coreness of each node (province) and their connections was plotted. From the dynamic angle, we also focused on the daily or weekly evolution of k_{max} as well as the number of nodes and edges. In addition, a group of scatter charts was drawn to describe the relationship between the coreness and characteristics of the provinces to demonstrate the common characteristics of important provinces in COVID-19 epidemic transmission. Most importantly, we could clearly present the hierarchical structure of the epidemic network by week. Finally,

we introduced the method of influence power to measure the transmission effects (outgoing and incoming) among provinces.

Results

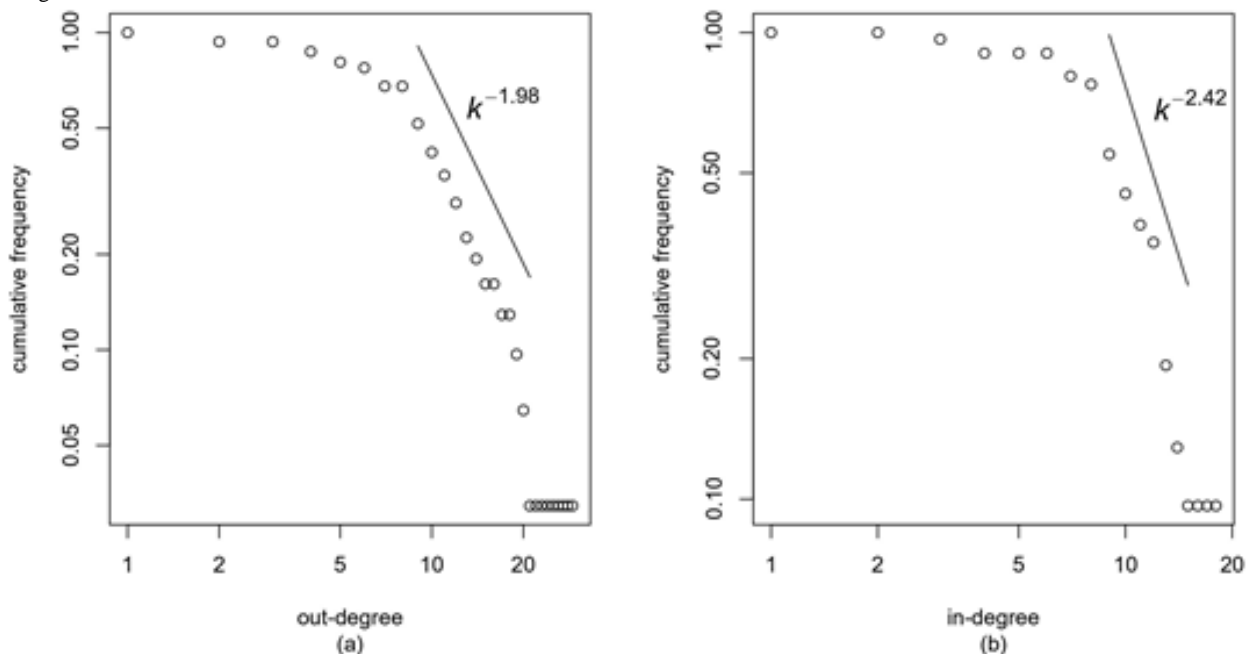
Degree Distribution

The method of degree distribution can offer a glimpse of the properties of a network. In the study of a network, the degree k of a node, which is regarded as the number of its direct neighbors, can be measured by the number of connections with other nodes. Hence, the degree distribution $P(k)$ relates to the probability that a randomly chosen node has k connections. Considering the directivity, the out-degree and in-degree are

the respective numbers of outgoing and incoming connections. Correspondingly, the probability that a randomly chosen node has out-degree k_{out} and in-degree k_{in} are represented by $P(k_{out})$ and $P(k_{in})$.

In terms of the COVID-19 epidemic network, where links are directed among 31 provinces, the cumulative out-degree and in-degree distributions are shown in Figure 2. We note that the cumulative frequency of the out-degrees (in-degrees) is the proportion of nodes in which the out-degree (in-degree) is not less than k . We can clearly see that they all follow the power law $P(k) \sim k^{-\gamma}$, and the values of the exponent γ are 1.98 and 2.42

Figure 2. Cumulative frequency graphs of the out-degrees and in-degrees. (a) The cumulative distribution of the out-degrees follows an approximate power law with exponent $\gamma=1.98$. (b) The cumulative distribution of the in-degrees follows an approximate power law with exponent $\gamma=2.42$. Both axes are in logarithmic scale.



To identify the transmission role of each province in the COVID-19 epidemic, a histogram describing the specific out-degrees and in-degrees of the 31 studied provinces is shown in Figure 3. In terms of the out-degree, the corresponding values of seven provinces (Xinjiang, Shanxi, Qinghai, Gansu, Guizhou, Ningxia, and Tibet) are less than 5; furthermore, the values for the provinces of Ningxia and Tibet are 0. The reason that few patients came from these provinces may be their location in the western part of mainland China, which has a relatively recessive economy and a less transient population. The provinces of Hubei, Beijing, and Guangzhou show the three highest out-degrees of 28, 19, and 18, respectively. Wuhan, the capital city of Hubei Province, was the first place to witness confirmed patients and is the epicenter of the epidemic outbreak. As two of the most developed provinces in mainland China, Beijing and Guangzhou had significant impacts on other provinces due to their larger transient populations. In the case of in-degree, three provinces (Xinjiang, Qinghai, and Tibet) have in-degrees <5 , and the three provinces with the highest values are Beijing, Henan, and Liaoning (all 17). Similarly, provinces with higher population mobility are more significantly affected than isolated provinces. The higher in-degrees of Henan and Liaoning may

be caused by the return of confirmed migrant laborers during the Spring Festival [26]. We also attempted to characterize the intuitive time attributes of the COVID-19 epidemic network, and we presented the evolution of the sum of the out-degrees (in-degrees) of the daily networks in Figure 4. The traveling route of a confirmed patient usually involves two different provinces as departure and destination, which means that one patient outbound relates to one inbound patient. Thus, the out-degrees of all nodes in a network are equal to its in-degrees. The sum of the out-degrees (in-degrees) shows an inverted U-shape, and the maximum was achieved on January 22, 2020. It can be seen that the complexity of COVID-19 epidemic network is time-varying, and it stood out on January 22, 2020.

After grasping some basic characteristics of the epidemic network, it is reasonable to assume that small groups of nodes organize in a hierarchical manner into increasingly large groups. However, the method of degree distribution lacks cognition of which node belongs to which layer, and the differences between layers are not sufficiently clear. K-core decomposition, which disentangles the hierarchical structure of networks by progressively focusing on their central cores, is of great use in obtaining the above detailed structural information.

Figure 3. Histogram describing the specific out-degrees and in-degrees of the 31 Chinese provinces in the COVID-19 epidemic network.

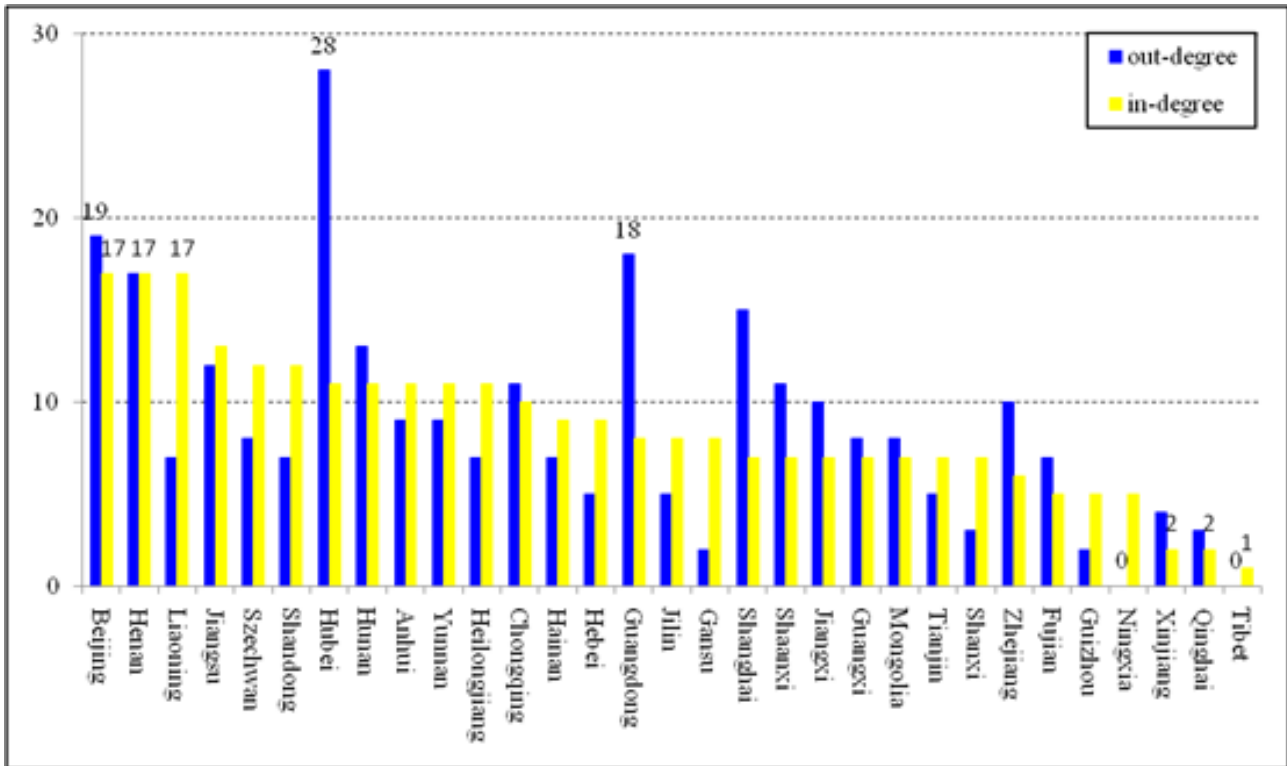
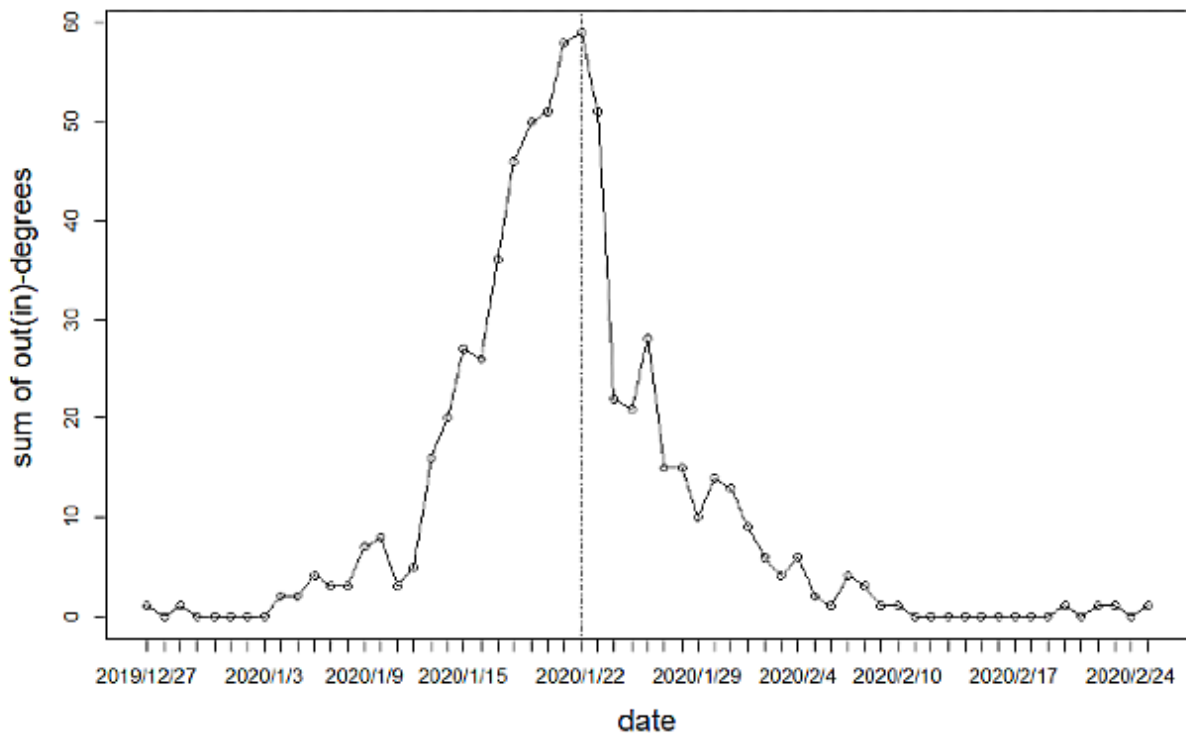


Figure 4. Evolution of the sum of the out-degrees (in-degrees) in the COVID-19 epidemic network for each day.



K-Core Decomposition

The generally accepted concept of k-core decomposition focuses more on the connections between nodes, while directionality can sometimes be ignored [16,18]. Specific to our COVID-19 network analysis, directionality was not taken into account in the application of k-core decomposition. Statically, the network relationship and the coreness of each node over the whole period

(from December 27, 2019, to February 25, 2020) are displayed in Figure 5. Here, it should be pointed out that a visualization software called Gephi [27] was used to exhibit the topological image in geospatial space to provide clear insight into the exact location of each node. It can be seen that there are 20 nodes with the highest coreness 13, accounting for 64.52% of 31 provinces, while the lowest coreness of 1 appears for the remote province of Tibet. More specifically, all provinces adjacent to

the outbreak area (Hubei Province) have the highest coreness values. In addition, Figure 6 plots the core size with respect to the coreness over the whole period. It can be seen that increasing coreness usually results in shrinking of the network. Combining Figure 5 with Figure 6, we can see that 25 nodes have corenesses

>8, and the nodes in the four innermost layers account for 80.65% of the entire epidemic network. These results further indicate that the COVID-19 epidemic affected the overwhelming majority of provinces in mainland China.

Figure 5. Topological image in geospatial space depicting the network relationship and the coreness of each node over the whole period. The color of the node represents its coreness, which corresponds to the k-shell it belongs to.

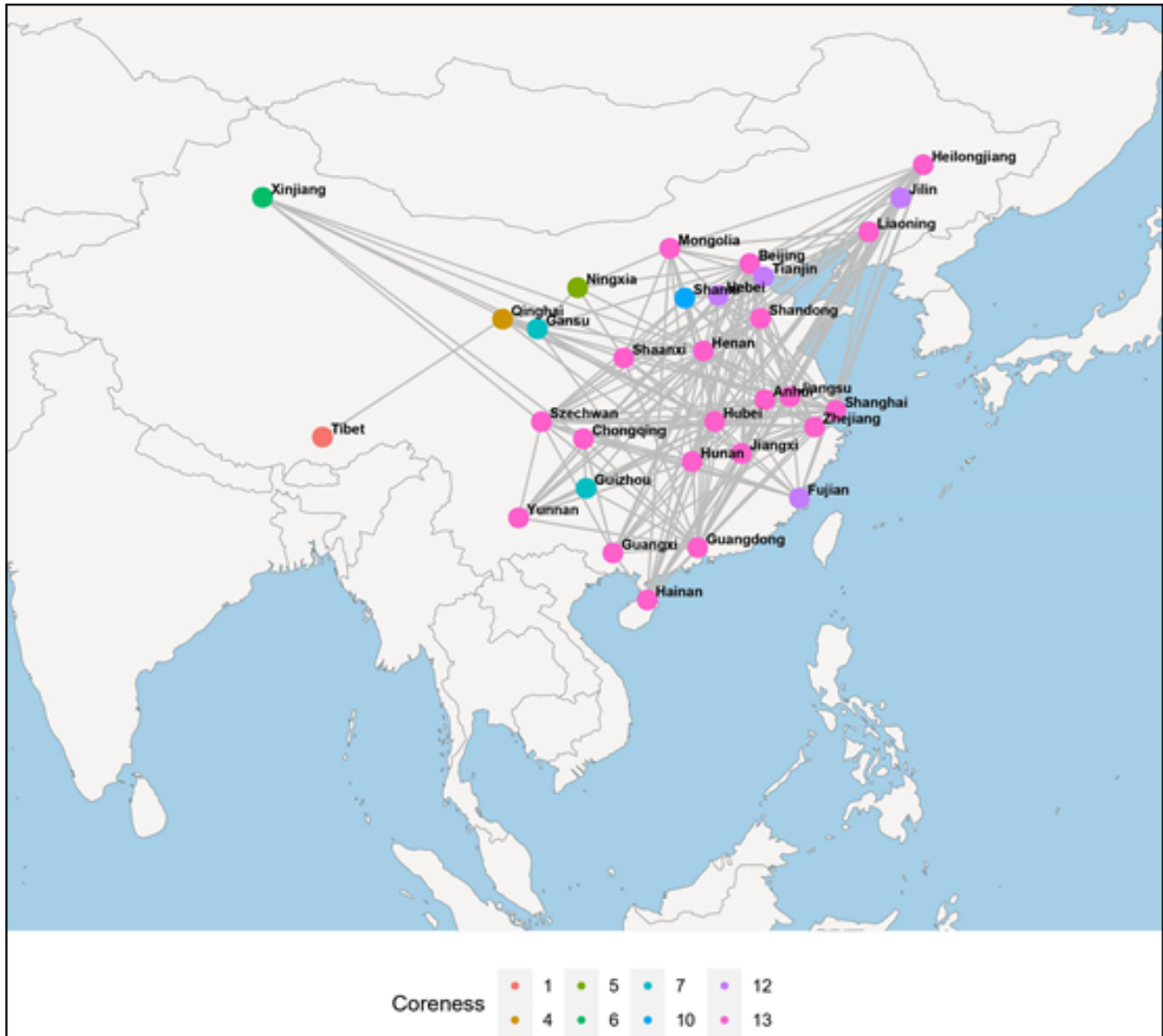
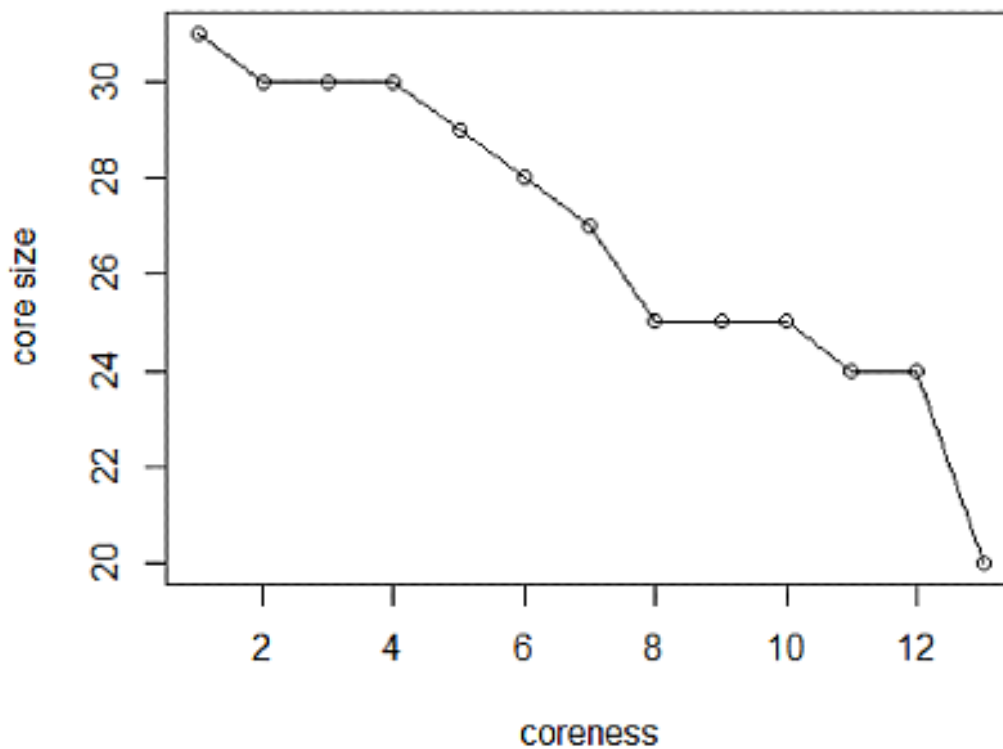


Figure 6. Plot of the core size versus the coreness of the network nodes over the whole study period. The core size represented in the vertical axis indicates the number of nodes with corenesses greater than or equal to the corresponding coreness on the horizontal axis.



To investigate which characteristics of the provinces are the key factors determining the coreness of each node, six variables (GDP per capita, population, volume of passenger transport, starting date of first-level response to major public health emergency, response time, and distance from Hubei Province) at the provincial level were introduced to draw a correlation diagram, as shown in Figure 7. Here, a logarithmic transformation was applied to the indicators of GDP per capita, population, volume of passenger transport, and distance from Hubei Province. It can be deduced from Figure 7 that the starting date of the first-level response to the major public health emergency and the distance from Hubei Province are significant negative correlation factors, while the other factors tend to be positively correlated. For example, we can reasonably assume that the starting date of the first-level response to the major public health emergency is related to the severity of the COVID-19 epidemic. The earlier the first-level response, the stronger the infection spread in that province. Generally, people carrying SARS-CoV-2 are more likely to be found in provinces with larger volumes of passenger transport, which also determines the importance of these provinces to the spread of the epidemic. These findings echo the analysis of the degree distribution to some extent.

In fact, the COVID-19 epidemic network is more likely to be dynamic than fixed over a period of time, and it is necessary to investigate its time-varying maximum coreness k_{\max} . Based on this, we first constructed daily epidemic networks, and Figure 8 presents the evolution of k_{\max} . The figure shows that there is

an obvious trend of initial rising and then falling for k_{\max} , and the maximum peak appears on January 21, 2020. We can conclude that the epidemic network from the end of January to the beginning of February is relatively complex. Considering the simple structure of the daily epidemic networks, the experiential patterns of summarized epidemic transmission are limited. Furthermore, the whole period can be divided into intervals, with a fixed window of 7 days.

Similar to Figure 8, Figure 9 shows the weekly evolutions of the maximum coreness k_{\max} , node number, and edge number. In terms of their common trends, there is a significant increase before the fourth week, at which point a steep decline appears; thus, the fourth week (January 17 to January 23, 2020) becomes its peak point. Considering the differences among the three, the number of nodes and edges goes up slightly after the eighth week. The above findings again confirm that the fourth week is the critical period of the COVID-19 epidemic outbreak, and the network structure formed in the surrounding weeks is relatively complex. The above statistical results depict the dynamic development of the COVID-19 epidemic. The outbreak and spread of COVID-19 led to a surge in the number of confirmed cases. The overwhelming majority of provinces started their first-level responses to the major public health emergency from January 23 to January 25, 2020, and many measures, such as isolating at home and wearing masks, were taken to contain the outbreak. The following swift drop in the number of confirmed cases demonstrates the effectiveness of these measures.

Figure 7. Correlation diagrams of the corenesses and characteristics of the provinces. The horizontal and vertical axes denote the characteristic variables and corenesses, respectively. The numbers in the lower right corner of each subgraph are the corresponding correlation coefficient. **5% significance, ***1% significance.

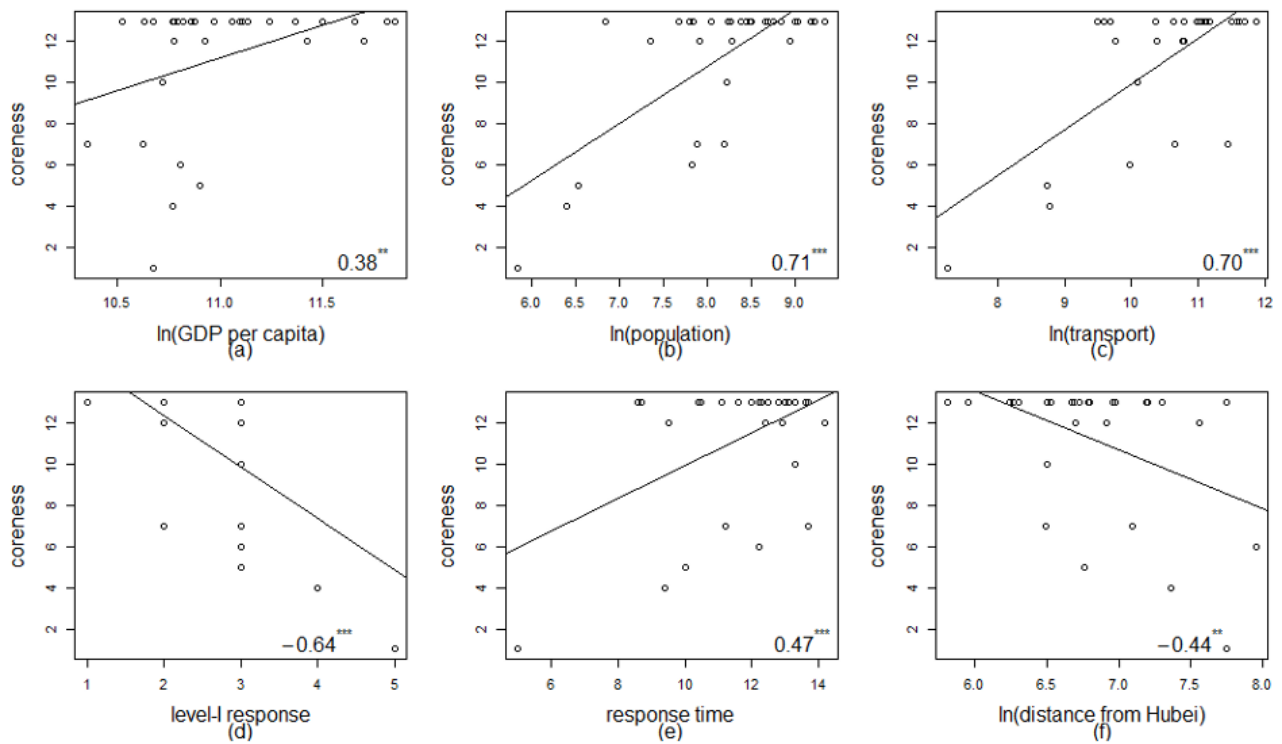


Figure 8. Daily evolution of the maximum coreness (k_{max}) in the COVID-19 epidemic network.

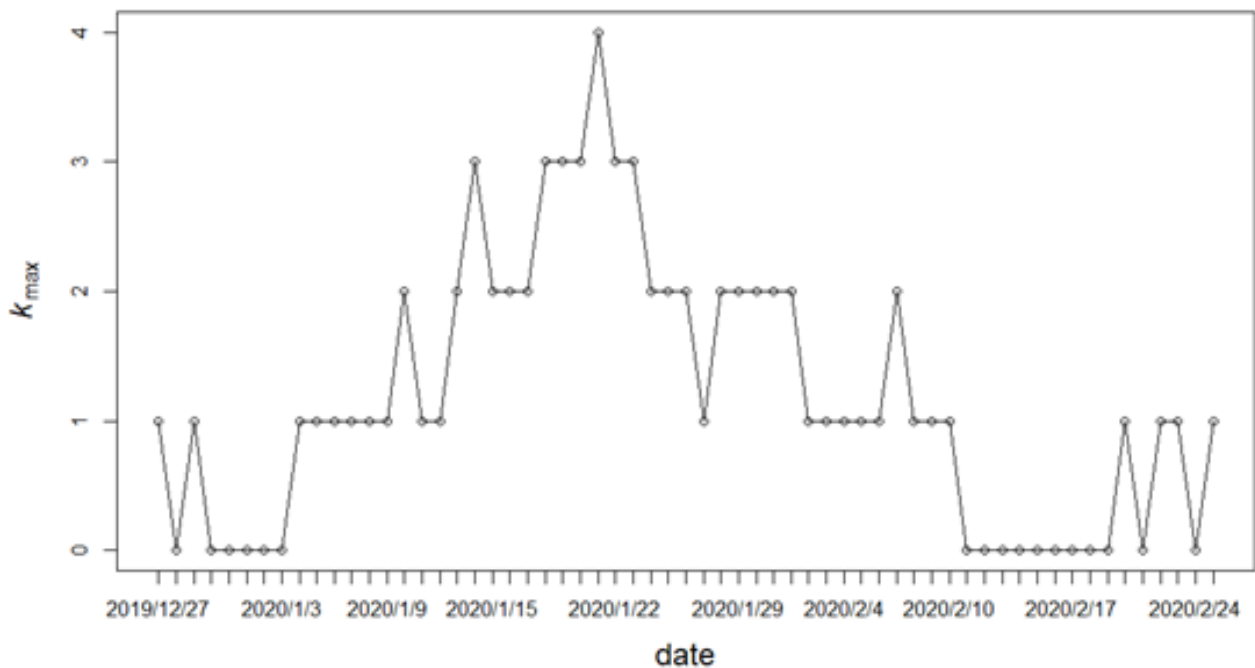
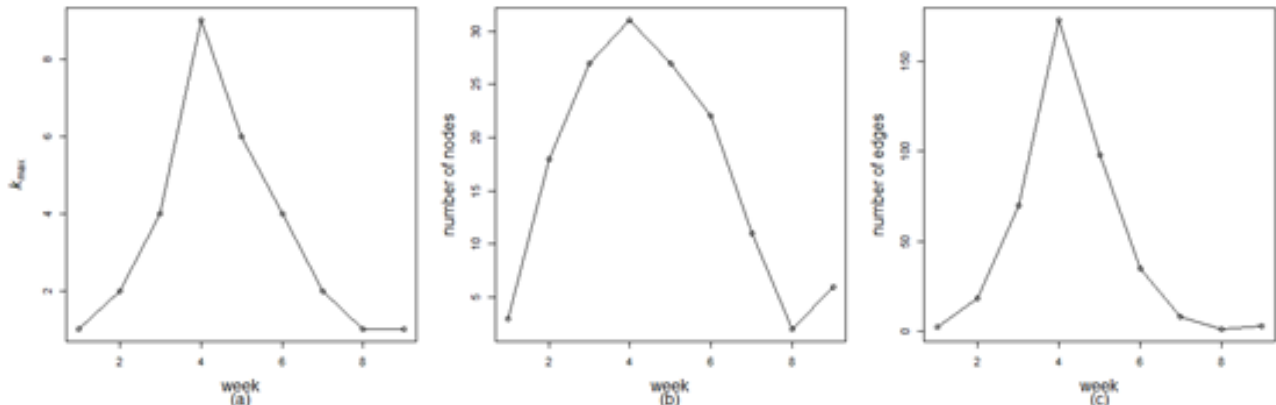


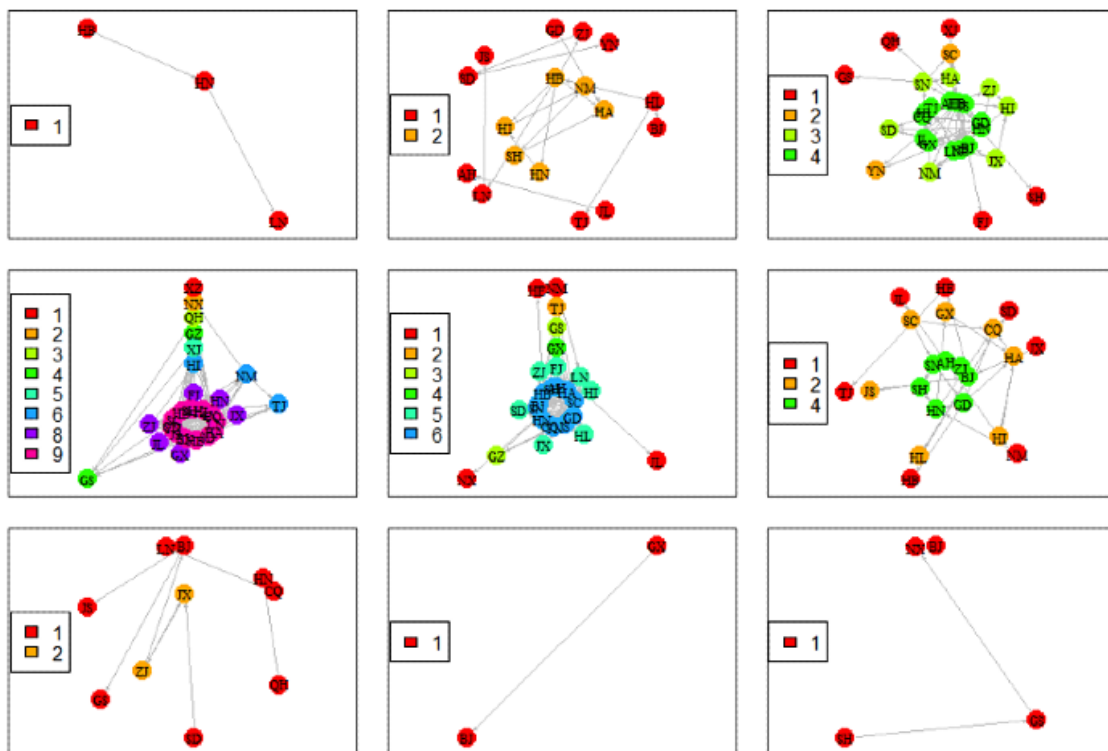
Figure 9. Evolutions of the maximum coreness (k_{max}), number of nodes, and number of edges in the weekly COVID-19 epidemic networks.



To visualize the epidemic transmission process dynamically, Figure 10 shows the node composition and hierarchical structure of the COVID-19 epidemic network by week. In general, the epidemic network structure corresponding to the third to sixth weeks tends to be more complex, and the fourth week stands out. Chinese spring rush may give a reasonable explanation. Taking the period from the third to sixth week as an example, there is no doubt that Tibet has kept the lowest coreness all the

way, while provinces of Anhui, Beijing and Guangdong show the highest coreness. There is a novel discovery about the changes of coreness in the epidemic outbreak area Hubei Province, which kept the highest level from the third to fifth week, and suddenly dropped to the lowest in the sixth week. To some extent, the two-week-lagging effective control of COVID-19 epidemic transmission by lockdown measures imposed by Wuhan government on January 23, 2020 is verified.

Figure 10. Dynamic networks of the COVID-19 epidemic showing the node composition and hierarchical structure. The color and label of each node denote the coreness and geographical province, respectively. The subgraphs from top to bottom and from left to right correspond to the nine weeks in order in the period from December 27, 2019 to February 25, 2020. AH: Anhui; BJ: Beijing; CQ: Chongqing; FJ: Fujian; GD: Guangdong; GS: Gansu; GX: Guangxi; GZ: Guizhou; HA: Henan; HB: Hubei; HE: Hebei; HI: Hainan; HL: Heilongjiang; HN: Hunan; JL: Jilin; JS: Jiangsu; JX: Jiangxi; LN: Liaoning; NM: Mongolia; NX: Ningxia; QH: Qinghai; SC: Szechwan; SD: Shandong; SH: Shanghai; SN: Shaanxi; SX: Shanxi; TJ: Tianjin; XJ: Xinjiang; XZ: Tibet; YN: Yunnan; ZJ: Zhejiang.



Influence Power

Epidemics generally occur in some regions first and then spread out rapidly when the situation in these regions becomes more serious and cannot be controlled. Specific to the network structure of an epidemic, the so-called outbreak or serious areas

have high centrality and occupy a certain shell. Naturally, after applying k-core decomposition to the COVID-19 epidemic network in a fixed period, the extent to which each k-shell will influence the other shells becomes a more attractive question. Here, the method of influence power can provide a good answer. Under the framework of influence power, there are two

indicators, out-strength and in-strength, that can respectively evaluate the power of each node to influence others and be influenced by others. Correspondingly, the calculation depends on the number of outgoing and incoming links. In terms of the COVID-19 epidemic network, if a large number of outgoing routes appear in one province, this province usually has a great transmission influence on other provinces. Similarly, if one province has a large number of incoming routes, it will also be greatly influenced by other provinces. Hence, the following formula can be used to further quantify the influence power η_k of the k-shell:



where η_k is the calculated ratio of the influence power and $L_{k-shell}$ relates to the number of outgoing (incoming) links in each k-shell of concern.

The results of influence power (out-strength and in-strength) of each shell and the innermost nodes based on the COVID-19 epidemic network in the whole period are shown in Table 1 and Table 2, respectively. The maximum coreness of the COVID-19 epidemic network is 13, and almost all the outgoing links (1164/1220, 95.41%) are from the provinces with the highest coreness. Among these provinces, more than half of the outgoing links (689/1220, 56.48%) come from Hubei Province, which is the origin of the COVID-19 epidemic. The provinces of

Guangdong and Beijing rank second and third, accounting for 4.51% (55/1220) and 3.77% (46/1220), respectively. Hainan Province, which is located in the same shell as Guangdong and Beijing, has the lowest proportion of outgoing links (7/1220, 0.57%). We can conclude that it is important to identify the key “outgoing” provinces for the prevention and control of the COVID-19 epidemic.

Furthermore, Table 2 can help us understand the “incoming” role of each shell and the innermost nodes in the transmission process of the COVID-19 epidemic. Consistent with the findings in Figure 5, the epidemic network in the whole period can be pruned recursively into 8 shells. In addition, there are nodes with incoming links in each shell. The highest proportion of incoming links, up to 86.80% (1059/1220), appears in the provinces with the highest corenesses. Among these provinces, the top three are Henan (152/1220, 12.46%), Szechwan (82/1220, 6.72%), and Guangxi (80/1220, 6.56%), while Zhejiang (16/1220, 1.31%) has the lowest proportion. Focusing on the breakout area of Hubei Province, there are only 28 incoming links (28/1220, 2.30%), in contrast to its largest number of outgoing links; this indicates that this province is less influenced by other provinces. On the whole, the in-strength performance of the provinces is different from the out-strength, and the “incoming” roles of these provinces tend to be more equal.


Table 1. Comparison of the out-strengths of each shell (coreness) and the innermost nodes (provinces) based on the COVID-19 epidemic network in the study period (N=1246 links), n (%).

Characteristic	Incoming links
Coreness	
4	3 (0.25)
6	5 (0.41)
7	6 (0.49)
10	3 (0.25)
12	39 (3.20)
13	1164 (95.41)
Province^a	
Hainan	7 (0.57)
Henan	33 (2.70)
Shaanxi	38 (3.11)
Hunan	42 (3.44)
Beijing	46 (3.77)
Guangdong	55 (4.51)
Hubei	689 (56.48)

^aBecause some nodes with 2 shells (Ningxia and Tibet) do not have outgoing links, only 6 shells of the COVID-19 epidemic network in the whole period are included in the table.

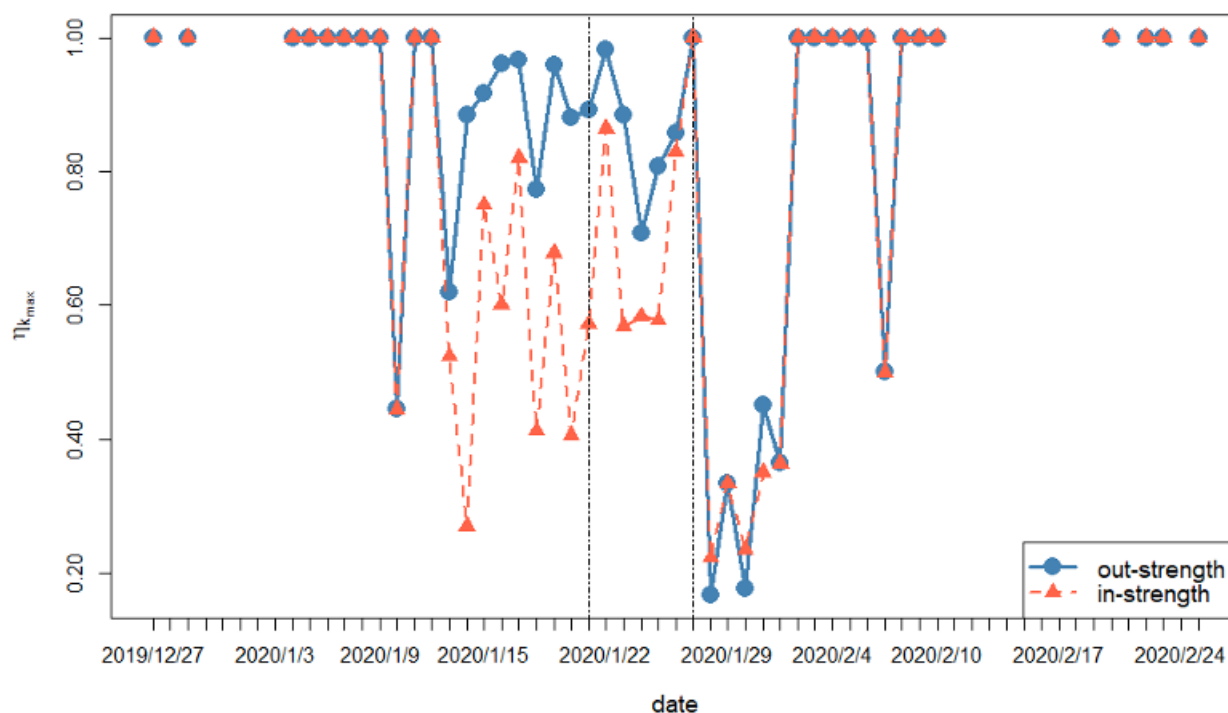
Table 2. Comparison of the in-strengths of each shell (coreness) and the innermost nodes (provinces) based on the COVID-19 epidemic network in the study period (N=1220 links), n (%).

Characteristic	Incoming links
Coreness	
1	1 (0.08)
4	5 (0.41)
5	5 (0.41)
6	2 (0.16)
7	27 (2.21)
10	22 (1.80)
12	99 (8.11)
13	1059 (86.80)
Province	
Zhejiang	16 (1.31)
Hubei	28 (2.30)
Liaoning	58 (4.75)
Jiangsu	63 (5.16)
Hunan	71 (5.82)
Guangxi	80 (6.56)
Szechwan	82 (6.72)
Henan	152 (12.46)

In some cases, the dynamic influence of a shell consisting of the most important nodes in the whole network is more worthy of attention. The above influence can also be measured by the method of influence power, which depends on the time-varying set of the innermost nodes and all the related directional links. On the basis of the daily COVID-19 epidemic networks, [Figure 11](#) presents the evolution of  from the perspectives of out-strength and in-strength, which elucidates the dynamic “outgoing” and “incoming” roles of those important provinces. It is notable that a relatively large gap between out-strength and

in-strength exists on January 21, 2020, which echoes the most complex daily network indicated in [Figure 8](#). We also observed that the out-strengths of the innermost nodes are larger than the in-strengths before January 27, 2020, which indicates that those provinces tend to have more influence on others rather than being influenced by others. After that, due to the stricter control measures imposed by those provinces, their out-strengths and the above contrast greatly weaken. To a certain extent, the above findings confirm the effectiveness of the control measures implemented by the Chinese government during the COVID-19 epidemic.

Figure 11. Daily evolution of the innermost shell from the perspectives of out-strength and in-strength in the COVID-19 epidemic network. The vertical dotted lines correspond to January 21, 2020, and January 27, 2020, respectively.



Discussion

Principal Findings

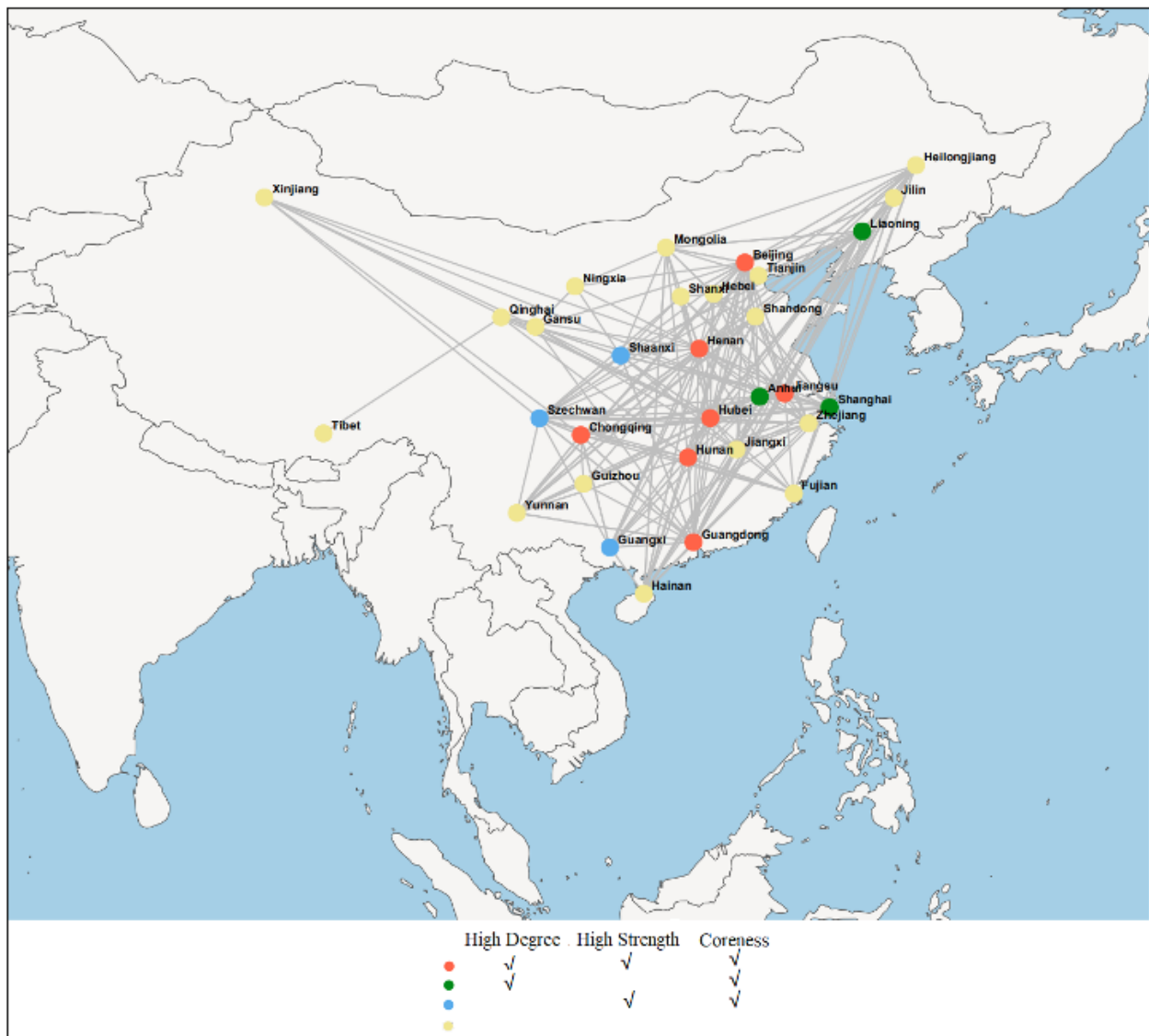
In economics, epidemiology, and many other fields, the increasing number of participants and volume of data further complicate the formation of networks. It is critical to extract effective information from these large and complex networks. Hence, it is necessary to identify and focus on the central nodes that drive the whole network instead of paying the same amount of attention to all the nodes. As mentioned above, degree distribution is the simplest way to measure the centrality of each node in a network; it only involves the local structure around the node. Specifically, in a binary network, the degree distribution depends on the number of edges of the considered node. In a directed network, the connecting edges of a node may have two directions, outgoing and incoming, which correspond to the out-degree and in-degree under the framework of degree distribution. Furthermore, the concept of degree has generally been extended to the sum of weights when analyzing a weighted directed network [28], and the strength (out-strength and in-strength) of nodes has been proposed. Additionally, to acquire more detailed information about a network structure, k-core decomposition can be employed to disentangle the hierarchical structure of the network by progressively focusing on its central core. In summary, the indicators of degree, coreness, and strength we adopted above can provide different perspectives to understand the nodes and structures of a network.

Taking the COVID-19 epidemic network over the whole period as an example, we calculated the degrees (out-degree and in-degree), strengths (out-strength and in-strength), and corenesses of all the nodes (31 provinces) in Table 3, and we plotted the geospatial network topology map, as shown in Figure 12. It should be emphasized that considering the diversity of the degrees and strengths of each node, the top 10 nodes were defined as having the highest degrees and highest strengths after ranking in descending order. In Figure 12, the color of the nodes indicates the intensities of the three indicators: degree, strength, and coreness. The red nodes correspond to high degree, high strength, and the highest coreness; the green nodes are representative of high degree and the highest coreness; the blue nodes denote high strength and the highest coreness; and the yellow nodes relate to other cases. Concerning the neighboring provinces of the outbreak area of Hubei, three provinces (Hunan, Henan, and Chongqing) show high degrees and strengths as well as the highest coreness. In the same case of the highest coreness, the degree of Anhui Province is high, the strength of Shaanxi Province is high, and neither the degree nor the strength of Jiangxi Province is high. After expanding the considered objects nationwide, due to their high values of degree, strength, and coreness, the provinces of Beijing, Guangdong, and Jiangsu can be regarded as the central nodes of the COVID-19 epidemic network. When analyzing the common characteristics of these three provinces, their high-mobility populations may provide the most reasonable explanation.

Table 3. Central properties of 31 provinces during the COVID-19 epidemic. The provinces are arranged in descending order according to the indicators of coreness and degree.

Province	Out-degree	In-degree	Degree	Out-strength	In-strength	Strength	Coreness
Hubei	28	11	39	689	28	717	13
Beijing	19	17	36	46	55	101	13
Henan	17	17	34	33	152	185	13
Guangdong	18	8	26	55	50	105	13
Jiangsu	12	13	25	26	63	89	13
Hunan	13	11	24	42	71	113	13
Liaoning	7	17	24	24	58	82	13
Shanghai	15	7	22	29	17	46	13
Chongqing	11	10	21	28	57	85	13
Szechwan	8	12	20	22	82	104	13
Anhui	9	11	20	26	56	82	13
Yunnan	9	11	20	18	43	61	13
Shandong	7	12	19	12	49	61	13
Heilongjiang	7	11	18	11	47	58	13
Shaanxi	11	7	18	38	49	87	13
Jiangxi	10	7	17	14	20	34	13
Hainan	7	9	16	7	49	56	13
Zhejiang	10	6	16	20	16	36	13
Guangxi	8	7	15	10	80	90	13
Mongolia	8	7	15	14	17	31	13
Hebei	5	9	14	13	43	56	12
Jilin	5	8	13	7	26	33	12
Fujian	7	5	12	10	18	28	12
Tianjin	5	7	12	9	12	21	12
Shanxi	3	7	10	3	22	25	10
Gansu	2	8	10	3	18	21	7
Guizhou	2	5	7	3	9	12	7
Xinjiang	4	2	6	5	2	7	6
Ningxia	0	5	5	0	5	5	5
Qinghai	3	2	5	3	5	8	4
Tibet	0	1	1	0	1	1	1

Figure 12. Topological image in geospatial space depicting the network relationship and the centrality of each node over the whole period. The colors of the nodes relate to the intensity of the degree, strength, and coreness.

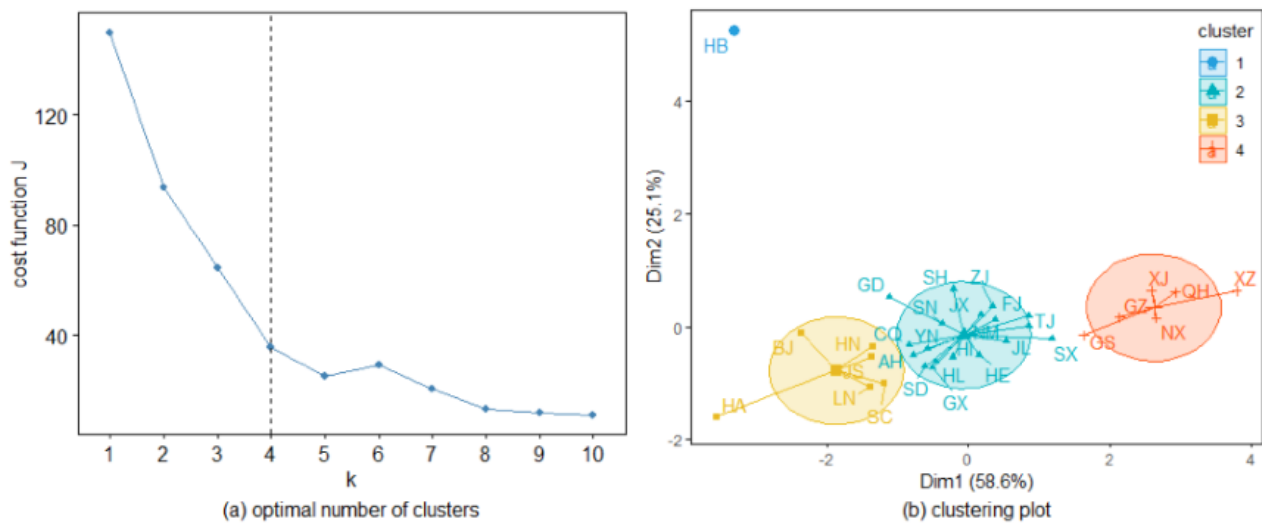


Some central properties of the 31 provinces during the COVID-19 epidemic are revealed in Table 3. Generally speaking, the maximum coreness of the COVID-19 epidemic network is 13, and provinces with high degrees and strengths tend to have the highest coreness. Furthermore, it can be seen that high strengths and low degrees exist in the provinces of Szechwan, Shaanxi, and Guangxi simultaneously, indicating that these provinces have strong interactions with few provinces. In contrast, the provinces of Liaoning, Anhui, and Shanghai have high degrees and relatively low strengths, which suggests that these provinces have weak interactions with numerous provinces. These findings are more likely to be related to the heterogeneous characteristics of those provinces, such as traffic, population, education, and weather.

Considering the direction of epidemic transmission, we drew a k-means clustering graph based on the indicators of out-degree,

in-degree, out-strength, in-strength, and coreness, as shown in Figure 13. The left panel presents the optimal number of clusters by the Elbow method, and the right panel visualizes the corresponding clusters. We can clearly see that the optimal clustering number of the 31 provinces is 4, and these four clusters obviously exist. Uniquely, Hubei Province formed a single cluster, which can be explained by its role as the initiator of the epidemic. The provinces of Beijing, Henan, Hunan, Jiangsu, Liaoning, and Szechwan are in the same group, and they show relatively high values of the above indicators. In contrast, provinces with lower values, such as Gansu, Guizhou, Ningxia, Qinghai, Tibet, and Xinjiang, belong to another cluster. The remaining provinces are also grouped together. This clustering is similar to that shown in Figure 12 and Table 3, and its uniqueness lies in considering directional factors when investigating the central properties of each province.

Figure 13. The optimal number of clusters and the clustering plot. The horizontal and vertical axes of the right panel represent the first and second principal components, respectively.



The findings in this section comprehensively demonstrate the important nodes in the COVID-19 epidemic network and reveal the transmission path among provinces in mainland China. On this basis, we can further identify some economic and social factors determining the development of this epidemic; finally, effective control can be achieved by imposing some public interventions. With more countries or territories involved in the COVID-19 epidemic, the structure of the world network has become more complex, and it is more urgent to explore the corresponding central properties.

In addition, we attempted to consider directionality in the empirical analysis of the COVID-19 epidemic network, and the results again confirmed the existing findings (see [Multimedia Appendix 1](#)).

Limitations

It is worth mentioning that our study is limited to the transmission of the COVID-19 epidemic in 31 provinces in mainland China, and the k -core decomposition is applicable to unweighted and undirected networks. In the future, more network analysis methods can be considered to explore the epidemic transmission dynamics involving more regions in China or the rest of the world.

Conclusions

The COVID-19 epidemic is spreading worldwide, and increasing numbers of countries and territories are becoming involved in the network of the outbreak. Identifying the most important nodes and the hierarchical structure of this network has become a priority. Focusing on mainland China, a COVID-19 epidemic network was constructed from the cross-provincial traveling records of confirmed patients; then, three methods, namely degree distribution, k -core decomposition, and influence power, were employed in further structural analysis of the network.

With regard to the empirical results of degree distribution, the power-law distribution suggests that most provinces have either low out-degrees or in-degrees, and only a small fraction of provinces tend to have relatively strong outward or inward

transmission effects. In descending order, the three provinces of Hubei, Beijing, and Guangzhou showed the highest out-degrees, and the three highest in-degrees were observed for the provinces of Beijing, Henan, and Liaoning.

The application of k -core decomposition also resulted in some novel findings. First, we verified the hierarchical structure of the COVID-19 epidemic network over the whole period, and more than half of the 31 provinces were found to be in the innermost core. Second, we considered the correlation of the characteristics and coreness of each province, and we identified some significant negative and positive factors. In addition, the variation of the maximum coreness with time was investigated from two perspectives: daily and weekly. An obvious trend of initial rising and subsequent falling appeared both on January 21, 2020, and in the fourth week. To be more specific, considering the dynamic transmission process of the COVID-19 epidemic, the three provinces of Anhui, Beijing, and Guangdong always showed the highest coreness from the third to the sixth week, and Hubei Province maintained the highest coreness until the fifth week but suddenly dropped to the lowest coreness in the sixth week.

Subsequently, the influence power (out-strength and in-strength) was introduced to measure the influence intensity of each k -shell. It was observed that most outgoing and incoming links were from the provinces with the highest corenesses. Moreover, we investigated the dynamic “outgoing” and “incoming” roles of those important provinces, and we found that the out-strength of the innermost nodes was larger than their in-strength before January 27, 2020, after which a reversal occurred.

Our study is committed to making policy recommendations to relevant departments. First, when a public emergency such as an epidemic breaks out, it is necessary to promptly adopt anti-epidemic measures (home isolation, wearing masks, etc), and mandatory traffic control should be implemented in a timely fashion to improve the emergency response. Second, measures such as the blockade of Wuhan should not only be implemented in the epicenter of the epidemic, but also in neighboring provinces and territories with high population mobility. The

level of the blockade can be determined according to the severity of the local epidemic situation. Finally, in view of the dynamic process of the COVID-19 epidemic, local health organizations should identify the epidemic stage and adjust the controlling measures in a timely fashion.

Acknowledgments

This work was financially supported by the University of International Business and Economics Huiyuan outstanding young scholars research funding (17YQ15) and the Fundamental Research Funds for the Central Universities in the University of International Business and Economics (CXTD10-10).

Conflicts of Interest

None declared.

Multimedia Appendix 1

Supplementary figures and table.

[DOCX File, 195 KB - [publichealth_v6i4e24291_app1.docx](#)]

References

1. Latinne A, Hu B, Olival KJ, Zhu G, Zhang L, Li H, et al. Origin and cross-species transmission of bat coronaviruses in China. *Nat Commun* 2020 Aug 25;11(1):4235 [FREE Full text] [doi: [10.1038/s41467-020-17687-3](https://doi.org/10.1038/s41467-020-17687-3)] [Medline: [32843626](https://pubmed.ncbi.nlm.nih.gov/32843626/)]
2. Timeline of WHO's response to COVID-19. World Health Organization. URL: <https://www.who.int/news/item/29-06-2020-covidtimeline> [accessed 2020-11-06]
3. The editors. Why COVID-19 has spread faster than SARS. *SupChina*. 2020 Apr 10. URL: <https://supchina.com/2020/04/10/why-covid-19-has-spread-faster-than-sars/> [accessed 2020-11-06]
4. China coronavirus: Lockdown measures rise across Hubei province. *BBC*. 2020 Jan 23. URL: <https://www.bbc.com/news/world-asia-china-51217455> [accessed 2020-11-06]
5. Leung G, Hedley A, Ho LM, Chau P, Wong IOL, Thach TQ, et al. The epidemiology of severe acute respiratory syndrome in the 2003 Hong Kong epidemic: an analysis of all 1755 patients. *Ann Intern Med* 2004 Nov 02;141(9):662-673 [FREE Full text] [doi: [10.7326/0003-4819-141-9-200411020-00006](https://doi.org/10.7326/0003-4819-141-9-200411020-00006)] [Medline: [15520422](https://pubmed.ncbi.nlm.nih.gov/15520422/)]
6. Anderson RM, Fraser C, Ghani AC, Donnelly CA, Riley S, Ferguson NM, et al. Epidemiology, transmission dynamics and control of SARS: the 2002-2003 epidemic. *Philos Trans R Soc Lond B Biol Sci* 2004 Jul 29;359(1447):1091-1105 [FREE Full text] [doi: [10.1098/rstb.2004.1490](https://doi.org/10.1098/rstb.2004.1490)] [Medline: [15306395](https://pubmed.ncbi.nlm.nih.gov/15306395/)]
7. Pang X, Zhu Z, Xu F, Guo J, Gong X, Liu D, et al. Evaluation of control measures implemented in the severe acute respiratory syndrome outbreak in Beijing, 2003. *JAMA* 2003 Dec 24;290(24):3215-3221. [doi: [10.1001/jama.290.24.3215](https://doi.org/10.1001/jama.290.24.3215)] [Medline: [14693874](https://pubmed.ncbi.nlm.nih.gov/14693874/)]
8. Wang J, Christakos G, Han W, Meng B. Data-driven exploration of 'spatial pattern-time process-driving forces' associations of SARS epidemic in Beijing, China. *J Public Health (Oxf)* 2008 Sep;30(3):234-244 [FREE Full text] [doi: [10.1093/pubmed/fdn023](https://doi.org/10.1093/pubmed/fdn023)] [Medline: [18441347](https://pubmed.ncbi.nlm.nih.gov/18441347/)]
9. Riley S, Fraser C, Donnelly CA, Ghani AC, Abu-Raddad LJ, Hedley AJ, et al. Transmission dynamics of the etiological agent of SARS in Hong Kong: impact of public health interventions. *Science* 2003 Jun 20;300(5627):1961-1966 [FREE Full text] [doi: [10.1126/science.1086478](https://doi.org/10.1126/science.1086478)] [Medline: [12766206](https://pubmed.ncbi.nlm.nih.gov/12766206/)]
10. Kaxiras E, Neofotistos G. Multiple Epidemic Wave Model of the COVID-19 Pandemic: Modeling Study. *J Med Internet Res* 2020 Jul 30;22(7):e20912 [FREE Full text] [doi: [10.2196/20912](https://doi.org/10.2196/20912)] [Medline: [32692690](https://pubmed.ncbi.nlm.nih.gov/32692690/)]
11. Zheng X, Zeng D, Sun A, Luo Y, Wang Q, Wang F. Network-based analysis of Beijing SARS data. In: Zeng D, Chen H, Rolka H, Lober B, editors. *Biosurveillance and Biosecurity*. BioSecure 2008. Lecture Notes in Computer Science, vol 5354. Berlin, Germany: Springer; 2008:64-73.
12. Adegboye OA, Elfaki F. Network Analysis of MERS Coronavirus within Households, Communities, and Hospitals to Identify Most Centralized and Super-Spreading in the Arabian Peninsula, 2012 to 2016. *Can J Infect Dis Med Microbiol* 2018;2018:6725284-6725289 [FREE Full text] [doi: [10.1155/2018/6725284](https://doi.org/10.1155/2018/6725284)] [Medline: [29854034](https://pubmed.ncbi.nlm.nih.gov/29854034/)]
13. Gong K, Kang L. A new k-shell decomposition method for identifying influential spreaders of epidemics on community networks. *Int J Syst Sci* 2018 Sep 26;6(4):366-375. [doi: [10.21078/jssi-2018-366-10](https://doi.org/10.21078/jssi-2018-366-10)]
14. Wang M, Li W, Guo Y, Peng X, Li Y. Identifying influential spreaders in complex networks based on improved k-shell method. *Physica A* 2020 Sep;554:124229. [doi: [10.1016/j.physa.2020.124229](https://doi.org/10.1016/j.physa.2020.124229)]
15. Zhang H, Zhao H, Cai W, Liu J, Zhou W. Using the k-core decomposition to analyze the static structure of large-scale software systems. *J Supercomput* 2009 May 20;53(2):352-369. [doi: [10.1007/s11227-009-0299-0](https://doi.org/10.1007/s11227-009-0299-0)]
16. He X, Zhao H, Cai W, Li G, Pei F. Analyzing the structure of earthquake network by k-core decomposition. *Physica A* 2015 Mar 1;421:34-43. [doi: [10.1016/j.physa.2014.11.022](https://doi.org/10.1016/j.physa.2014.11.022)]

17. Fitzhugh S, Butts C. Patterns of co-membership: Techniques for identifying subgraph composition. *Soc Networks* 2018 Oct;55:1-10. [doi: [10.1016/j.socnet.2018.03.006](https://doi.org/10.1016/j.socnet.2018.03.006)]
18. Angelou K, Maragakis M, Argyrakis P. A structural analysis of the patent citation network by the k-shell decomposition method. *Physica A: Statistical Mechanics and its Applications* 2019 May 1;521:476-483. [doi: [10.1016/j.physa.2019.01.063](https://doi.org/10.1016/j.physa.2019.01.063)]
19. Seidman S. Network structure and minimum degree. *Soc Networks* 1983 Sep;5(3):269-287. [doi: [10.1016/0378-8733\(83\)90028-x](https://doi.org/10.1016/0378-8733(83)90028-x)]
20. Carmi S, Havlin S, Kirkpatrick S, Shavitt Y, Shir E. A model of Internet topology using k-shell decomposition. *Proc Natl Acad Sci USA* 2007 Jul 03;104(27):11150-11154 [FREE Full text] [doi: [10.1073/pnas.0701175104](https://doi.org/10.1073/pnas.0701175104)] [Medline: [17586683](https://pubmed.ncbi.nlm.nih.gov/17586683/)]
21. Erdős P, Hajnal A. On chromatic number of graphs and set-systems. *Acta Math Acad Sci Hung* 1966 Mar 17;17(1-2):61-99. [doi: [10.1007/bf02020444](https://doi.org/10.1007/bf02020444)]
22. Lick D, White A. K-degenerate graphs. *Canad J Math* 2018 Nov 20;22(5):1082-1096. [doi: [10.4153/cjm-1970-125-1](https://doi.org/10.4153/cjm-1970-125-1)]
23. Kong Y, Shi G, Wu R, Zhang Y. K-core: Theories and applications. *Phys Rep* 2019 Nov 10;832:1-32. [doi: [10.1016/j.physrep.2019.10.004](https://doi.org/10.1016/j.physrep.2019.10.004)]
24. Cross-provincial traveling data. URL: <http://2019ncov.ifacehub.com/api.html>
25. Yu Y. CHINA_SPATDWM: Stata module to provide spatial distance matrices for Chinese provinces and cities. Statistical Software Components S457059, Boston College Department of Economics. 2009. URL: <https://ideas.repec.org/c/boc/bocode/s457059.html> [accessed 2020-11-06]
26. Chen Z, Zhang Q, Lu Y, Guo ZM, Zhang X, Zhang WJ, et al. Distribution of the COVID-19 epidemic and correlation with population emigration from Wuhan, China. *Chin Med J (Engl)* 2020 May 05;133(9):1044-1050 [FREE Full text] [doi: [10.1097/CM9.0000000000000782](https://doi.org/10.1097/CM9.0000000000000782)] [Medline: [32118644](https://pubmed.ncbi.nlm.nih.gov/32118644/)]
27. The Open Graph Viz Platform. Gephi. URL: <https://gephi.org/> [accessed 2020-10-10]
28. Barrat A, Barthélemy M, Pastor-Satorras R, Vespignani A. The architecture of complex weighted networks. *Proc Natl Acad Sci USA* 2004 Mar 16;101(11):3747-3752 [FREE Full text] [doi: [10.1073/pnas.0400087101](https://doi.org/10.1073/pnas.0400087101)] [Medline: [15007165](https://pubmed.ncbi.nlm.nih.gov/15007165/)]

Abbreviations

GDP: gross domestic product

SARS: sudden acute respiratory syndrome

WHO: World Health Organization

Edited by G Eysenbach; submitted 13.09.20; peer-reviewed by M Chen, RA De Carvalho; comments to author 03.10.20; revised version received 18.10.20; accepted 25.10.20; published 13.11.20.

Please cite as:

Qin L, Wang Y, Sun Q, Zhang X, Shia BC, Liu C

Analysis of the COVID-19 Epidemic Transmission Network in Mainland China: K-Core Decomposition Study

JMIR Public Health Surveill 2020;6(4):e24291

URL: <http://publichealth.jmir.org/2020/4/e24291/>

doi: [10.2196/24291](https://doi.org/10.2196/24291)

PMID: [33108309](https://pubmed.ncbi.nlm.nih.gov/33108309/)

©Lei Qin, Yidan Wang, Qiang Sun, Xiaomei Zhang, Ben-Chang Shia, Chengcheng Liu. Originally published in *JMIR Public Health and Surveillance* (<http://publichealth.jmir.org>), 13.11.2020. This is an open-access article distributed under the terms of the Creative Commons Attribution License (<https://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in *JMIR Public Health and Surveillance*, is properly cited. The complete bibliographic information, a link to the original publication on <http://publichealth.jmir.org>, as well as this copyright and license information must be included.

Original Paper

Reinfection with SARS-CoV-2: Discrete SIR (Susceptible, Infected, Recovered) Modeling Using Empirical Infection Data

Andrew McMahon¹, BA, MSci; Nicole C Robb^{1,2}, BSc, DPhil

¹Department of Physics, University of Oxford, Oxford, United Kingdom

²Warwick Medical School, University of Warwick, Coventry, United Kingdom

Corresponding Author:

Andrew McMahon, BA, MSci

Department of Physics

University of Oxford

Parks Road

Oxford, OX1 3PJ

United Kingdom

Phone: 44 1865272357

Email: andrew.mcmahon@physics.ox.ac.uk

Abstract

Background: The novel coronavirus SARS-CoV-2, which causes the COVID-19 disease, has resulted in a global pandemic. Since its emergence in December 2019, the virus has infected millions of people, caused the deaths of hundreds of thousands, and resulted in incalculable social and economic damage. Understanding the infectivity and transmission dynamics of the virus is essential to determine how best to reduce mortality while ensuring minimal social restrictions on the lives of the general population. Anecdotal evidence is available, but detailed studies have not yet revealed whether infection with the virus results in immunity.

Objective: The objective of this study was to use mathematical modeling to investigate the reinfection frequency of COVID-19.

Methods: We have used the SIR (Susceptible, Infected, Recovered) framework and random processing based on empirical SARS-CoV-2 infection and fatality data from different regions to calculate the number of reinfections that would be expected to occur if no immunity to the disease occurred.

Results: Our model predicts that cases of reinfection should have been observed by now if primary SARS-CoV-2 infection did not protect individuals from subsequent exposure in the short term; however, no such cases have been documented.

Conclusions: This work concludes that infection with SARS-CoV-2 provides short-term immunity to reinfection and therefore offers useful insight for serological testing strategies, lockdown easing, and vaccine development.

(JMIR Public Health Surveill 2020;6(4):e21168) doi:[10.2196/21168](https://doi.org/10.2196/21168)

KEYWORDS

infectious disease; SARS-CoV-2; COVID-19; SIR; modeling; reinfection

Introduction

The novel coronavirus SARS-CoV-2 is thought to have originated in China in late 2019, and has since spread globally, resulting in the COVID-19 pandemic. In the 8 months since the first confirmed case, the virus has resulted in 24 million confirmed infections and over 820,000 deaths, and has caused substantial social and economic damage.

SIR (Susceptible, Infected, Recovered) modeling uses a set of differential equations to determine how the number of infected and recovered individuals changes over time given a specified rate of infection and recovery. It was first used in 1927 by

Kermack et al [1] and has since been used to model epidemics from AIDS [2] to SARS (severe acute respiratory syndrome) [3]. Variations of SIR modeling have been used during the COVID-19 pandemic to look at the varying burden on health care systems based on public health intervention [4], the absence of a stable disease-free equilibrium [5], and infection rate [6], as well as the eventual size of the overall pandemic [7]. An extension of the model has also been used to simulate the changing death rate as a function of the number of individuals infected, and it was found that an equilibrium point was reached where there were no further reinfections [8].

In this study, we used an extension to the SIR framework that distinguished between infected and reinfected individuals to model empirical data taken from a compiled COVID-19 data set [9], in order to investigate the reinfection frequency of the disease. We aimed to determine if cases classified as “reinfections” will occur, although to date there is no definitive cases of reinfection reported in the scientific literature.

Methods

Data Sources

We used national infection and mortality data from a variety of sources to investigate the reinfection dynamics of SARS-CoV-2. Unless specified, national data on infections and deaths from SARS-CoV-2 were acquired from the Our World in Data database compiled by the Oxford Martin School at the University of Oxford [9]; the hospitalization cases in Switzerland were obtained from the Federal Office of Public Health in Switzerland [10]; the data for the city of New York were obtained from the New York City Health website [11]; the population of New York City was obtained from the 2019 New York census [12]; and the recovery data for Germany was sourced from Trading Economics [13], which obtains its data from the World Health Organization (WHO). For each geographical region, the data were taken from the date of the first recorded infection up until May 17, 2020, when the data were accessed.

Choice of Geographical Regions

The simulations were initially completed for the United Kingdom, where, at the time the data were accessed, there was a high number of confirmed cases. Australia was selected as an example of a region with low numbers of recorded cases, in order to investigate the limit of expected reinfections; Germany was selected as it was one of the few countries with recorded recovery data; Italy was studied since the number of infections and deaths had peaked by May 17, 2020; Singapore was unique as a city-state so population density for the nation was very high; Switzerland was selected since hospitalization data were available at the time the data were accessed; and the United

States as a whole was compared with New York City, which was the worst affected part of the United States at the time.

Assumptions

A number of assumptions have been made. Where possible, they have been made so that the number of reinfections is underestimated. These assumptions are as follows:

1. There is a large lag time for recovery to take place (28 days) [14,15].
2. The incubation period was modeled as 6 days [16].
3. The model does not consider social distancing or shielding and so assigns an equal probability of an infection to all individuals.
4. Not all infections have been recorded due to lack of testing, misdiagnosis, or asymptomatic infection [17].
5. Infections and recoveries are not necessarily recorded on the date that they first occurred.
6. There is no emigration out of, or immigration into, a population of interest.
7. The model assumes a homogeneous population density, with no societal structure (eg, equal number of residents per household).

The Model

We based our model on the compartmental SIR framework, but differentiated between initial and subsequent infections, resulting in a 6-state model (susceptible, infected, recovered, infected [2 or more times], recovered [2 or more times], and deceased) (Figure 1 and Table 1). The number of infections and deaths each day was taken from national statistics (as described above). Where available, recovery data were used; otherwise, recoveries were modeled with a 28-day lag time (with the number of recoveries representing those individuals who did not die during the 28-day recovery time). “Recovered” individuals were selected stochastically from the populations of the states 28 days prior [14,15], “infected” individuals from the populations of the states 6 days prior (due to the incubation period [16]), and “deceased” individuals from the populations of the states 1 day prior.

Figure 1. A simple representation of the model. S_t represents the number of persons susceptible to infection who have had no prior infections on day t ; I_t is the number of people currently infected for the first time on day t ; R_t is the number of people who have recovered once on day t ; I'_t is the number of people who have been infected 2 or more times and are infected on day t ; R'_t is the number of people who have recovered 2 or more times and are not infected on day t of the model, and D_t is the number of deceased persons on day t of the model. Further symbols are defined in Table 1.

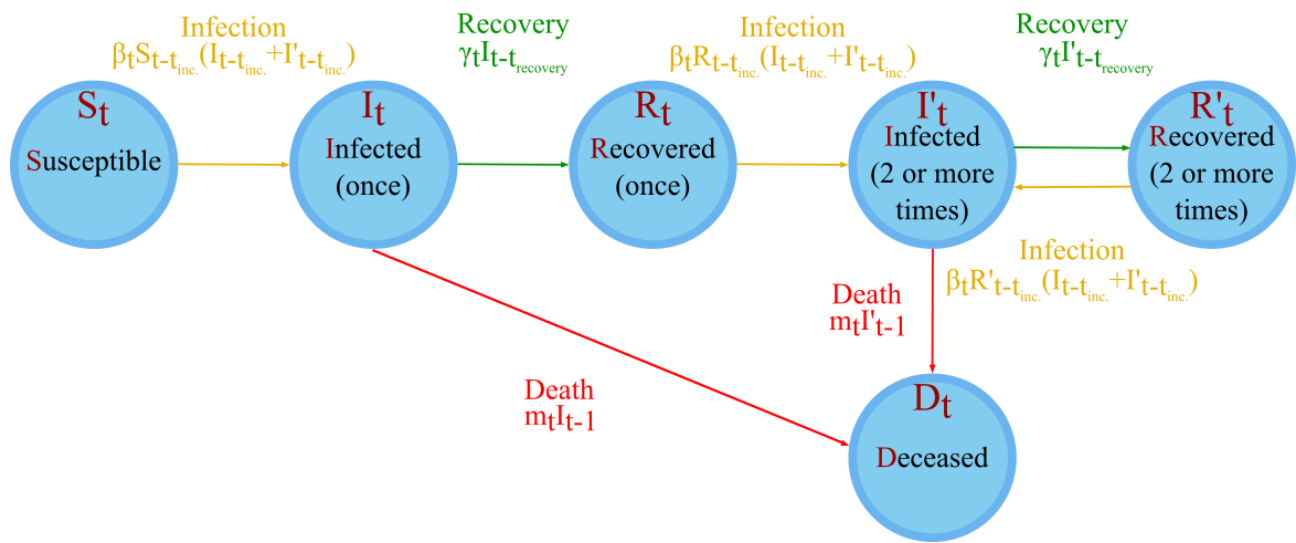


Table 1. Definition of parameters in the model.

Parameter	Definition
x_i	Random number
t	The number of days into the simulation; $t=1$ for the day of the first infection
$t_{recovery}$	The average number of days for recovery ($t_{recovery}=28$)
$t_{incubation} = t_{inc.}$	The average number of days before an infection is seen ($t_{incubation}=6$)
t_{max}	The number of days over which the simulation is run
S_t	The number of susceptible individuals on day t
I_t	The number of infected (once) individuals on day t
R_t	The number of recovered (once) individuals on day t
I'_t	The number of infected (2 or more times) individuals on day t
R'_t	The number of recovered (2 or more times) individuals on day t
D_t	The number of deceased individuals from SARS-CoV-2 on day t
B_t	The infection rate on day t
γ	The recovery rate on day t
m_t	The death rate on day t
N	The total population in the model; $N = S_t + I_t + R_t + I'_t + R'_t + D_t \forall t$
$N_t^{infected}$	The number of infected individuals on day t ; $N_t^{infected} = I_t + I'_t$
$N_t^{uninfected}$	The number of uninfected individuals on day t ; $N_t^{uninfected} = S_t + R_t + R'_t$
$n_t^{infected}$	The number of new infections on day t ; $n_t^{infected} = \beta_t S_{t-t_{incubation}} (I_{t-t_{incubation}} + I'_{t-t_{incubation}}) + \beta_t R_{t-t_{incubation}} (I_{t-t_{incubation}} + I'_{t-t_{incubation}}) + \beta_t R'_{t-t_{incubation}} (I_{t-t_{incubation}} + I'_{t-t_{incubation}})$
$n_t^{recovered}$	The number of recovering individuals on day t ; $n_t^{recovered} = \gamma I_{t-t_{recovery}} + \gamma I'_{t-t_{recovery}}$
n_t^{deaths}	The number of deaths on day t ; $n_t^{deaths} = m_t I_{t-1} + m_t I'_{t-1}$
$i_t^{first\ time}$	The number of first-time infections on day t (ie, the number of $S_t \rightarrow I_t$ transitions on day t)

When using the model, the rates of infection, recovery, and fatality for each state were assumed to be independent of how many infections a host had previously had. The number of susceptible persons at the beginning of the simulation, N , was taken to be the population of the region of interest [9,12]. After all infections, recoveries, and deaths for a day, the number of days into the simulation was increased by one, $t \rightarrow t + 1$ up to t_{\max} . The simulation was repeated 10,000 times to produce expectation values and standard deviations for the number of individuals classified as reinfections.

By pooling the number of cases in the infected (2 or more times), recovered (2 or more times), and deceased (after 2 or more infections) states at the end of the simulation, we calculated an estimate of the number of reinfections that would be expected to occur. This number represents the total population that had passed through the infected (2 or more times) state by the end of the simulation.

Unless otherwise stated, the average recovery time used in the simulations was set as 28 days, as this is greater than the median recovery time suggested in the report of the WHO-China Joint Mission on Coronavirus Disease 2019 [14].

Results

Simulations of UK Infection Data Suggest a Small Number of Reinfections Should Have Occurred

We initially ran the simulation for data in the United Kingdom over the course of 106 days (from the first recorded case on February 1 until May 17, 2020, when the data were accessed). Figure 2 shows how the population of each state in the model changed over the course of a typical simulation. The number of susceptible individuals initially remained steady, until day 55, when there was a sharp decline due to the increase in primary infections (Figure 2A). The number of individuals infected just once started to increase steadily after day 40 and continued to do so throughout the simulation until day 92. After the 28-day lag time, the individuals infected once started to recover, resulting in an increase in the recovered (once) state through to the end of the simulation (Figure 2B). As the number of recovered individuals started to increase, so did the number of people infected for a second time. The number of people recovered for the second time started to increase after the 28-day recovery lag time (Figure 2C). The number of deaths started to rise from day 55 onwards, and fatalities continued to increase through to the end of the simulation (Figure 2D). In the United Kingdom, the number of expected reinfections was calculated to be 43 (SD 7), which makes up 0.018% of the total infections (Table 2). The first reinfection for the United Kingdom was on day 82 (SD 5), corresponding to April 22, 2020.

Figure 2. Plots of the populations of each state in the model over the course of a typical simulation, using infection data from the United Kingdom. (A) An example plot of the susceptible population in the model over the course of 106 days (from the first recorded case on February 1 until May 17, 2020, when the data were accessed). (B) An example plot of the populations that are infected for the first time or recovered from a single infection. (C) An example plot of the populations of the simulation that have been reinfected and have recovered from an infection twice. (D) An example plot of the number of deceased individuals through the course of the simulation.

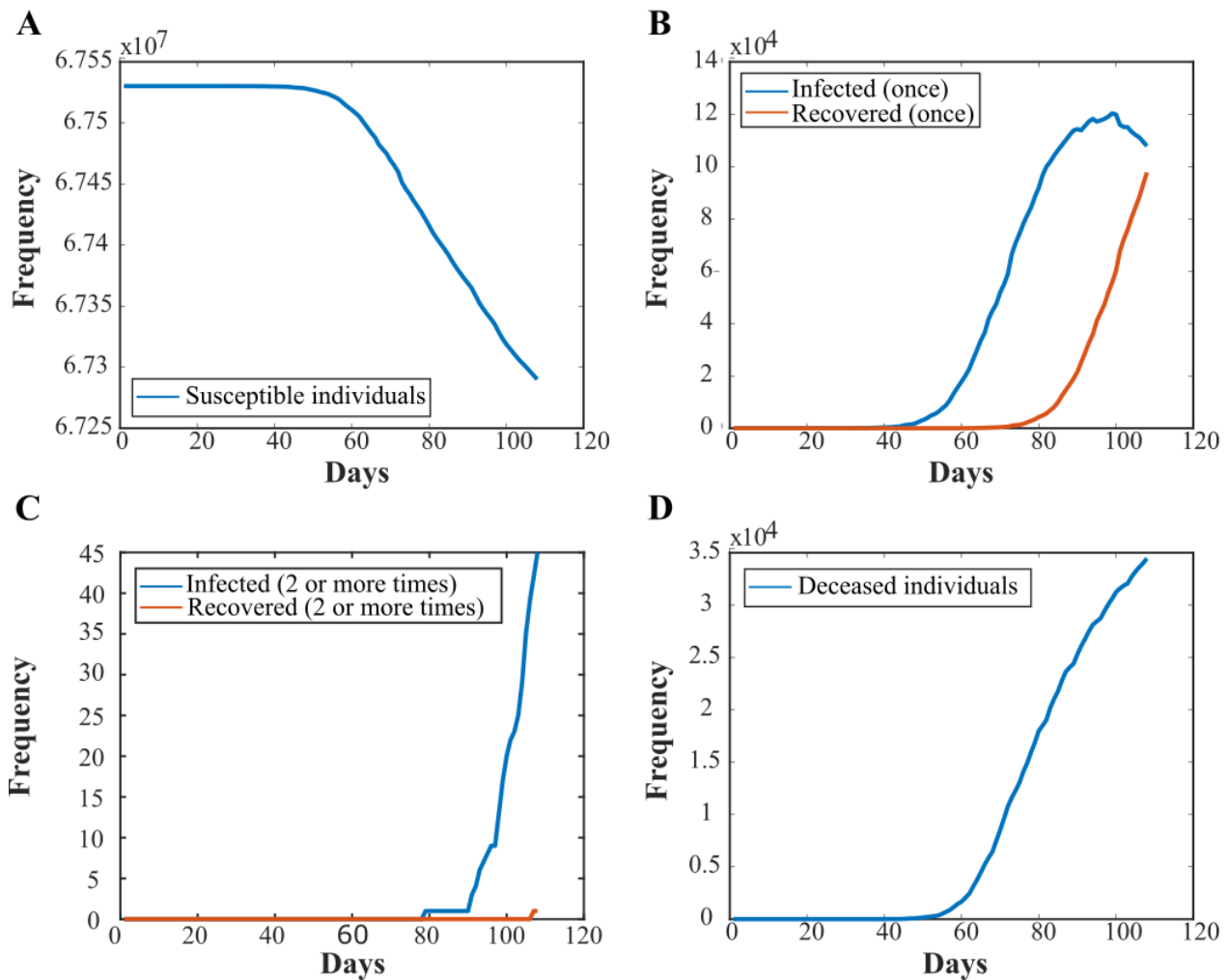


Table 2. The number of predicted reinfections and their standard deviation in different locations worldwide as predicted from the model. Unless otherwise stated, these figures represent simulations using the total number of infections for each region and are modeled without the data on the number of recoveries.

Region	Reinfections, mean (SD)	Infections, N	Reinfections as a % of the total infections
Australia	0.1 (0.3)	7036	0.0014
Germany	20 (5)	174,355	0.011
Germany (with recovery data)	79 (9)	174,355	0.05
Italy	63 (8)	224,760	0.028
New York City	209 (15)	189,027	0.11
New York City (hospitalizations)	7 (3)	48,462	0.004
Singapore	4 (2)	27,356	0.014
Switzerland	4 (2)	30,587	0.013
United Kingdom	43 (7)	240,161	0.018
United States	402 (20)	1,467,884	0.027

Simulations of Infection Data in Other Regions Show a Similar Trend

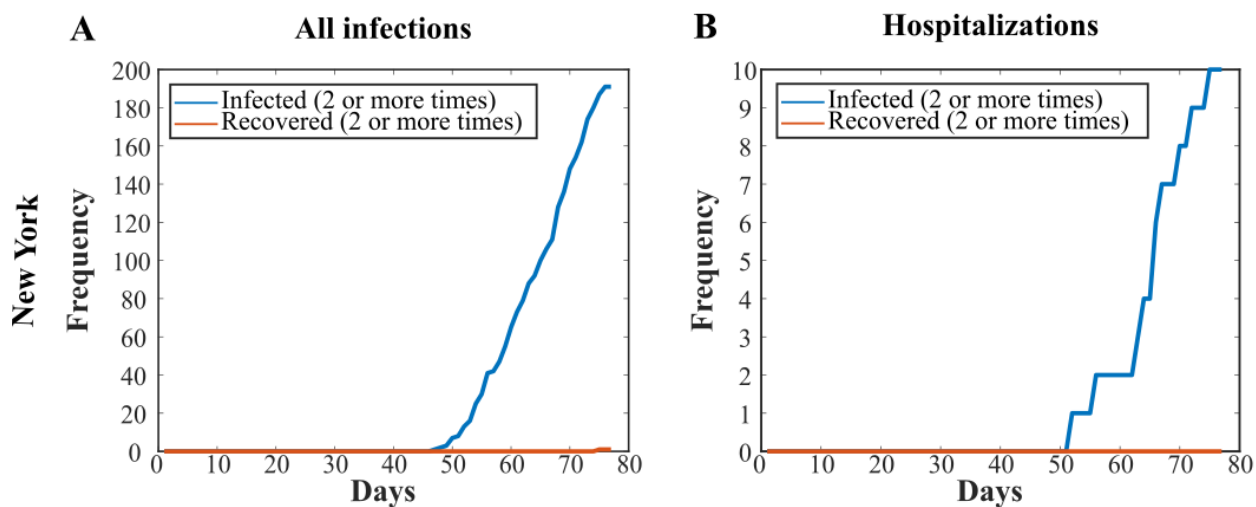
The simulations were repeated with data from Australia, Italy, New York City, Singapore, Switzerland, and the United States. The mean number of expected reinfections in each region or country for the 10,000 simulations that were run are shown in Table 2. In all cases, with the exception of Australia, our model predicts that reinfection cases should occur.

Comparison of Infection and Hospitalization Data in New York City

Next, we repeated our simulation for New York City, with the total number of infections replaced by the number of

hospitalizations. When we ran the simulation with an input of the total number of infections, the number of secondary infections continued to increase throughout the simulation, when the numbers appear to start to peak (Figure 3A). This was followed by an increase in the number of secondary recoveries after the 28-day recovery lag time. In comparison, the hospitalization data for New York showed no secondary recoveries as the reinfections occurred later into the simulation (Figure 3B). The total number of predicted reinfections from the New York hospitalized data was 12 (SD 4) (Table 2).

Figure 3. Comparison of total infections versus hospitalization data in New York City. Plots of the infected (2 or more times) and recovered (2 or more times) states for (A) New York using all infection data and (B) New York using only the hospitalization data.

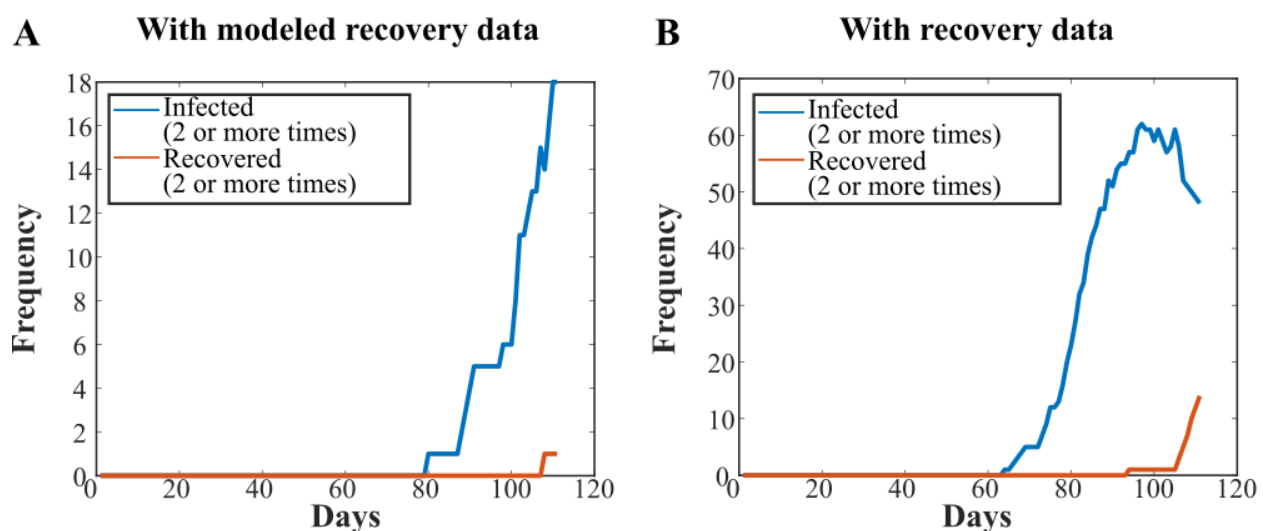


Inclusion of Recovery Data Suggests That Predicted Reinfections Are Underestimated

Recovery data was sparse or unavailable for most regions, likely due to lack of follow-up testing. Recovery data were available from Germany, and we therefore compared the results of our

simulation for Germany with and without the recovery data as an input. The models used a 28-day lag before the recoveries started, meaning very few secondary recoveries took place (Figure 4A and B). There were 73 more reinfections with the reinfection data than with the modeled data (Table 2).

Figure 4. Plots of infected (2 or more times) and recovered (2 or more times) states with (A) modeled recovery data and (B) actual recovery data. Use of actual recovery data from Germany suggests that the number of recovered individuals, and hence reinfections, are underestimated in our model.



The 28-day lag time used for the modeled recovery data ensured that we underestimated the recovery rate, and therefore the rate of reinfection as well. To investigate a more life-like recovery rate, the United Kingdom simulations were repeated again using the modeled recovery data, while shortening the lag time for recovery. As expected, we found that the rate of reinfection increased as the lag time was decreased from 28 days through to 7 days, as there was a larger population that recovered from a primary infection. With a 7-day lag time, the number of people in the infected (2 or more times) state peaked at day 101 of the simulation ([Multimedia Appendix 1](#)). The total number of people reinfected throughout the simulation increased as the lag time decreased, with 43 (SD 7), 83 (SD 9), 139 (SD 12), and 209 (SD 14) reinfections for 28-day, 21-day, 14-day, and 7-day recovery lag times, respectively.

Discussion

In this work, we have presented a modeling strategy used to determine whether SARS-CoV-2 reinfections can occur. We modeled actual infection and fatality data from different regions around the world and found that all regions investigated, with the exception of Australia, should have recorded cases of reinfections if primary infection with SARS-CoV-2 did not provide some level of immunity. The actual number of cases of reinfection that have been reported in any of these regions or countries to date is zero, suggesting that worldwide, primary SARS-CoV-2 infection provides short-term immunity.

In Australia, the number of confirmed SARS-CoV-2 infections at the time the data were accessed was relatively low [9], possibly due to early social distancing measures, the closing of international borders, and mass testing and tracing measures. The number of modeled reinfections (0.1 [SD 0.3]; [Table 2](#)) reflects this, and so even without immunity from infection no reinfections would be expected to occur. Similarly, in Switzerland and Singapore, very low numbers of reinfections were predicted by the model (6.2 [SD 2.5] and 6 [SD 2], respectively; [Table 2](#)). It is possible that these very low numbers of reinfection cases could have been missed due to misdiagnosis or lack of follow-up testing. We therefore applied our model to data from Germany [9], Italy [9], New York City [11,12], and the United States as a whole [9], which have recorded far higher numbers of SARS-CoV-2 infections (174,355; 224,760; 189,027; and 1,467,884, respectively, when the data were accessed). The number of reinfection cases predicted for these countries was 30 (SD 6), 89 (SD 9), 335 (SD 18), and 635 (SD 25) for Germany, Italy, New York, and the United States, respectively ([Table 2](#)). We conclude that it is therefore very unlikely that all of these predicted cases, if true, were missed due to misdiagnosis or lack of testing.

We also found that rehospitalization cases should have been seen amongst hospitalized cases in New York City—it is unlikely that these cases would be missed as people are processed and tested on admission into hospital. To date, however, no reinfections have verifiably been recorded anywhere in the world. A report from South Korea suggested that 116 patients recovered from COVID-19 had tested positive by RT-PCR (reverse transcription–polymerase chain reaction)

for the virus again [18]; however, this has since been explained as the “false-positive” detection of remnants of viral RNA (ribonucleic acid) rather than reactivation or reinfection. The lack of documented reinfections suggests that short-term immunity to the virus is produced by an initial infection, although our model cannot predict whether this immunity will last over longer timescales.

Our results are supported by a number of animal challenge studies, which also show that immunity to SARS-CoV-2 can be conferred. A study in rhesus macaques showed that, following initial viral clearance, the monkeys showed a reduction in their median viral load in comparison with primary infection when rechallenged with SARS-CoV-2 [19]. Similarly, Ryan et al [20] demonstrated that rechallenged ferrets were fully protected from acute lung pathology. An adenovirus-vector vaccine tested on rhesus macaques elicited a humoral and cellular response that, on challenge with the virus, proved to significantly reduce the viral load in bronchoalveolar lavage fluid and respiratory tract tissue [21]. However, a longitudinal study by Seow et al [22] showed that the immunity conferred against SARS-CoV-2 may only be short term. Our model proposes that reinfection cases should have already started to appear by April 2020, suggesting a possible lower limit for immunity duration.

A report from the WHO-China Joint Mission on Coronavirus Disease 2019 estimated the recovery time for SARS-CoV-2 infection to be 2 weeks for mild cases and 3–6 weeks for severe or critical cases [14]; based on this we used a long (28 days) recovery lag time in the modeled data. Comparison with real-world recovery data from Germany suggested that the actual recovery time may be significantly shorter, giving rise to an underestimation of the reinfection rate in our modeled data. This was supported by an increase in the number of predicted reinfections in the UK simulations when we used a shorter recovery lag time of 7, 14, or 21 days. In addition, there were no allowances in our model for transmission being localized to regions smaller than a nation or city; the daily infection data were likely to be only a fraction of the total number of infections due to asymptomatic or mild infections not being recorded, and infections were recorded on the date of testing, not the actual date of infection. We also note that significant differences in testing, reporting, and shielding of the vulnerable exist between the different regions in this study and that a large number of COVID-19 cases were missed in every region of interest (eg, in Geneva, unreported cases were estimated to be 11.6 infections per reported infection from April 6 to May 9 [17]). In every region, we expect that the impact on our simulation would be to underestimate the number of reinfections. Taken together, this suggests that the actual reinfection rate would be significantly higher than that predicted by our model if there was no immunity conferred by prior infection.

Our model has a number of limitations, including the lack of modeling of any social structure, the fact that individuals who have been infected may change their shielding behaviors, differing recovery times from person to person, and missing information regarding immigration into and out of regions of interest. In spite of this, the results documented here provide strong evidence, based on real data, to suggest that there is at least short-term immunity conferred by an initial infection

of SARS-CoV-2. This has implications for serological testing strategies, lockdown easing timescales, and vaccine development. Our modeling strategy can also be extended to understand the reinfection dynamics of future pandemics.

Acknowledgments

We thank Dr Barak Gilboa for a critical reading of the manuscript. This work was supported by a Royal Society Dorothy Hodgkin Research Fellowship (DKR00620) and a Research Grant for Research Fellows (RGF\R1\180054) to NCR. Data and code available on request.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Plots of infected (2 or more times) and recovered (2 or more times) populations in the United Kingdom when the lag time used was (A) 28 days, (B) 21 days, (C) 14 days, and (D) 7 days. Use of lower recovery lag times leads to an increase in the number of expected reinfections.

[PDF File (Adobe PDF File), 314 KB - [publichealth_v6i4e21168_app1.pdf](#)]

References

1. Kermack WO, McKendrick AG, Walker GT. A contribution to the mathematical theory of epidemics. *Proc R Soc Lond A* 1997 Jan;115(772):700-721. [doi: [10.1098/rspa.1927.0118](#)]
2. Victor Okhuese A. Estimation of the Probability of Reinfection With COVID-19 by the Susceptible-Exposed-Infectious-Removed-Undetectable-Susceptible Model. *JMIR Public Health Surveill* 2020 May 13;6(2):e19097 [FREE Full text] [doi: [10.2196/19097](#)] [Medline: [32369029](#)]
3. Ng TW, Turinici G, Danchin A. A double epidemic model for the SARS propagation. *BMC Infect Dis* 2003 Sep 10;3(1):19 [FREE Full text] [doi: [10.1186/1471-2334-3-19](#)] [Medline: [12964944](#)]
4. Ming W, Zhang C. Breaking down of healthcare system: mathematical modelling for controlling the novel coronavirus (2019-nCoV) outbreak in Wuhan, China. *bioRxiv Preprint* posted online January 30, 2020. [doi: [10.1101/2020.01.27.922443](#)]
5. Victor A. Mathematical predictions for COVID-19 as a global pandemic. *SSRN Journal* 2020:e. [doi: [10.2139/ssrn.3555879](#)]
6. Nesteruk I. Statistics based predictions of coronavirus 2019-nCoV spreading in mainland China. *medRxiv Preprint* posted online February 13, 2020. [doi: [10.1101/2020.02.12.20021931](#)]
7. Batista M. Estimation of the final size of the COVID-19 epidemic. *medRxiv Preprint* posted online February 28, 2020. [doi: [10.1101/2020.02.16.20023606](#)]
8. Okhuese AV. Estimation of the Probability of Reinfection With COVID-19 by the Susceptible-Exposed-Infectious-Removed-Undetectable-Susceptible Model. *JMIR Public Health Surveill* 2020 May 13;6(2):e19097 [FREE Full text] [doi: [10.2196/19097](#)] [Medline: [32369029](#)]
9. Ritchie H, Roser M, Ortiz-Ospina E, Hasell J. Coronavirus pandemic (COVID-19) - Country by country. *Our World in Data*. 2020. URL: <https://ourworldindata.org/coronavirus> [accessed 2020-05-17]
10. New coronavirus: Situation in Switzerland. Federal Office of Public Health. 2020. URL: <https://www.bag.admin.ch/bag/en/home/krankheiten/ausbrueche-epidemien-pandemien/aktuelle-ausbrueche-epidemien/novel-cov/situation-schweiz-und-international.html> [accessed 2020-05-17]
11. Covid-19: Data. NYC Health. 2020. URL: <https://www1.nyc.gov/site/doh/covid/covid-19-data.page> [accessed 2020-05-17]
12. United States Census Bureau. QuickFacts: Richmond County (Staten Island Borough), New York; New York County (Manhattan Borough), New York; Bronx County (Bronx Borough), New York; Kings County (Brooklyn Borough), New York; Queens County (Queens Borough), New York. *Census.gov*. 2019. URL: tinyurl.com/ybmwj89r [accessed 2020-05-17]
13. Germany Coronavirus Recovered. *Trading Economics*. 2020. URL: <https://tradingeconomics.com/germany/coronavirus-recovered> [accessed 2020-05-17]
14. Report of the WHO-China Joint Mission on Coronavirus Disease 2019 (COVID-19). *World Health Organization*. 2020 Feb. URL: <https://www.who.int/docs/default-source/coronaviruse/who-china-joint-mission-on-covid-19-final-report.pdf> [accessed 2020-05-17]
15. Bi Q, Wu Y, Mei S, Ye C, Zou X, Zhang Z, et al. Epidemiology and transmission of COVID-19 in 391 cases and 1286 of their close contacts in Shenzhen, China: a retrospective cohort study. *The Lancet Infectious Diseases* 2020 Aug;20(8):911-919 [FREE Full text] [doi: [10.1016/s1473-3099\(20\)30287-5](#)]
16. Backer JA, Klinkenberg D, Wallinga J. Incubation period of 2019 novel coronavirus (2019-nCoV) infections among travellers from Wuhan, China, 20-28 January 2020. *Euro Surveill* 2020 Feb;25(5):e [FREE Full text] [doi: [10.2807/1560-7917.ES.2020.25.5.2000062](#)] [Medline: [32046819](#)]

17. Stringhini S, Wisniak A, Piumatti G, Azman AS, Lauer SA, Baysson H, et al. Seroprevalence of anti-SARS-CoV-2 IgG antibodies in Geneva, Switzerland (SEROCoV-POP): a population-based study. *The Lancet* 2020 Aug;396(10247):313-319. [doi: [10.1016/s0140-6736\(20\)31304-0](https://doi.org/10.1016/s0140-6736(20)31304-0)]
18. Cha S, Smith J. Explainer: South Korean findings suggest 'reinfected' coronavirus cases are false positives. Reuters. 2020 May 7. URL: <https://www.reuters.com/article/us-health-coronavirus-southkorea-explain-idUSKBN22J0HR> [accessed 2020-05-17]
19. Chandrashekar A, Liu J, Martinot AJ, McMahan K, Mercado NB, Peter L, et al. SARS-CoV-2 infection protects against rechallenge in rhesus macaques. *Science* 2020 Aug 14;369(6505):812-817 [FREE Full text] [doi: [10.1126/science.abc4776](https://doi.org/10.1126/science.abc4776)] [Medline: [32434946](https://pubmed.ncbi.nlm.nih.gov/32434946/)]
20. Ryan K, Bewley K, Fotheringham S, Brown P, Hall Y, Marriott AC, et al. Dose-dependent response to infection with SARS-CoV-2 in the ferret model: evidence of protection to re-challenge. *bioRxiv Preprint* posted May 29, 2020. [doi: [10.1101/2020.05.29.123810](https://doi.org/10.1101/2020.05.29.123810)]
21. van Doremalen N, Lambe T, Spencer A, Belij-Rammerstorfer S, Purushotham JN, Port JR, et al. ChAdOx1 nCoV-19 vaccination prevents SARS-CoV-2 pneumonia in rhesus macaques. *bioRxiv Preprint* posted online May 13, 2020. [doi: [10.1101/2020.05.13.093195](https://doi.org/10.1101/2020.05.13.093195)]
22. Seow J, Graham C, Merrick B, Acors S, Steel KJA, Hemmings O, et al. Longitudinal evaluation and decline of antibody responses in SARS-CoV-2 infection. *medRxiv Preprint* posted online July 11, 2020. [doi: [10.1101/2020.07.09.20148429](https://doi.org/10.1101/2020.07.09.20148429)]

Abbreviations

RNA: ribonucleic acid

RT-PCR: reverse transcription–polymerase chain reaction

SARS: severe acute respiratory syndrome

SIR: Susceptible, Infected, Recovered

WHO: World Health Organization

Edited by T Sanchez; submitted 09.06.20; peer-reviewed by M Salman, S Case; comments to author 20.07.20; revised version received 31.08.20; accepted 22.09.20; published 16.11.20.

Please cite as:

McMahon A, Robb NC

Reinfection with SARS-CoV-2: Discrete SIR (Susceptible, Infected, Recovered) Modeling Using Empirical Infection Data

JMIR Public Health Surveill 2020;6(4):e21168

URL: <http://publichealth.jmir.org/2020/4/e21168/>

doi: [10.2196/21168](https://doi.org/10.2196/21168)

PMID: [33052872](https://pubmed.ncbi.nlm.nih.gov/33052872/)

©Andrew McMahon, Nicole C Robb. Originally published in *JMIR Public Health and Surveillance* (<http://publichealth.jmir.org>), 16.11.2020. This is an open-access article distributed under the terms of the Creative Commons Attribution License (<https://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in *JMIR Public Health and Surveillance*, is properly cited. The complete bibliographic information, a link to the original publication on <http://publichealth.jmir.org>, as well as this copyright and license information must be included.

Original Paper

COVID-19 Surveillance in a Primary Care Sentinel Network: In-Pandemic Development of an Application Ontology

Simon de Lusignan¹, MD; Harshana Liyanage¹, PhD; Dylan McGagh¹, BSc; Bhautesh Dinesh Jani², MBChB; Jorgen Bauwens³, MSc, MPH; Rachel Byford¹, BSc; Dai Evans⁴, BSc, MBBS; Tom Fahey⁵, MSc, MD; Trisha Greenhalgh¹, FMedSci; Nicholas Jones¹, MBBS, MSc; Frances S Mair², MBMChB, MD; Cecilia Okusi¹, MRES; Vaishnavi Parimalanathan¹, MPH; Jill P Pell², MSc, MD; Julian Sherlock¹, BSc; Oscar Tamburis⁶, MEng, PhD; Manasa Tripathy¹, BSc, MSc; Filipa Ferreira¹, BEng, MSc, PhD; John Williams¹, MSc, FRCGP, FFCI; F D Richard Hobbs¹, FMedSci, FRCGP, MA, FRCP

¹Nuffield Department of Primary Care Health Sciences, University of Oxford, Oxford, United Kingdom

²General Practice and Primary Care, Institute of Health and Wellbeing, University of Glasgow, Glasgow, United Kingdom

³University Children's Hospital Basel, University of Basel, Basel, Switzerland

⁴PRIMIS, University of Nottingham, Nottingham, United Kingdom

⁵Department of General Practice, Royal College of Surgeons, Ireland, Dublin, Ireland

⁶Department of Veterinary Medicine and Animal Productions, University of Naples Federico II, Naples, Italy

Corresponding Author:

Simon de Lusignan, MD

Nuffield Department of Primary Care Health Sciences

University of Oxford

Radcliffe Primary Care Building

Radcliffe Observatory Quarter, Woodstock Rd

Oxford, OX2 6GG

United Kingdom

Phone: 44 1865617283

Email: simon.delusignan@phc.ox.ac.uk

Abstract

Background: Creating an ontology for COVID-19 surveillance should help ensure transparency and consistency. Ontologies formalize conceptualizations at either the domain or application level. Application ontologies cross domains and are specified through testable use cases. Our use case was an extension of the role of the Oxford Royal College of General Practitioners (RCGP) Research and Surveillance Centre (RSC) to monitor the current pandemic and become an in-pandemic research platform.

Objective: This study aimed to develop an application ontology for COVID-19 that can be deployed across the various use-case domains of the RCGP RSC research and surveillance activities.

Methods: We described our domain-specific use case. The actor was the RCGP RSC sentinel network, the system was the course of the COVID-19 pandemic, and the outcomes were the spread and effect of mitigation measures. We used our established 3-step method to develop the ontology, separating ontological concept development from code mapping and data extract validation. We developed a coding system-independent COVID-19 case identification algorithm. As there were no gold-standard pandemic surveillance ontologies, we conducted a rapid Delphi consensus exercise through the International Medical Informatics Association Primary Health Care Informatics working group and extended networks.

Results: Our use-case domains included primary care, public health, virology, clinical research, and clinical informatics. Our ontology supported (1) case identification, microbiological sampling, and health outcomes at an individual practice and at the national level; (2) feedback through a dashboard; (3) a national observatory; (4) regular updates for Public Health England; and (5) transformation of a sentinel network into a trial platform. We have identified a total of 19,115 people with a definite COVID-19 status, 5226 probable cases, and 74,293 people with possible COVID-19, within the RCGP RSC network (N=5,370,225).

Conclusions: The underpinning structure of our ontological approach has coped with multiple clinical coding challenges. At a time when there is uncertainty about international comparisons, clarity about the basis on which case definitions and outcomes are made from routine data is essential.

KEYWORDS

COVID-19; medical informatics; sentinel surveillance

Introduction

The COVID-19 pandemic has many features of a complex system [1,2]. Complexities include repeated name changes of both the causative organism and associated disease [3-6], evolving understanding of core clinical features at presentation [7,8], and differing rates of testing and approaches to outcome reporting between countries [9,10]. This complexity presents a significant challenge for consistent clinical coding within computerized medical records (CMR) systems [11].

Creating an ontology for COVID-19 surveillance should help to facilitate reproducibility and interoperability between various key stakeholders, from clinicians and epidemiologists to data scientists and software developers. Ontologies are formalizations of conceptualizations and exist in reference or application formats [12]. Reference ontologies are at a domain level and describe a group of related concepts. Application ontologies are more specific and are used when modeling across multiple domains [13]. Application ontologies should be evaluated against a testable use case, which represents the scope and requirements of the specific application [14,15]. The emergence of a new disease means that corresponding original ontologies need to be developed.

We report the development of a COVID-19 application ontology using the Oxford Royal College of General Practitioners (RCGP) Research and Surveillance Centre (RSC) network's adaptations to COVID-19 as its use case. The RCGP RSC is an established primary care sentinel network, which extracts pseudonymized data from a nationally representative sample of over 500 general practices twice weekly (N=5,370,225) [16]. RCGP RSC has collaborated with Public Health England (PHE) for over 50 years, conducting influenza and respiratory disease surveillance and vaccine effectiveness studies [17,18]. The RCGP RSC has extended these routine surveillance activities to include monitoring the spread of COVID-19, assessing the effectiveness of containment measures, and becoming a platform for an in-pandemic COVID-19 trial [19,20].

Building on our previous experience of developing ontologies [12,21,22], we created an application ontology for extended COVID-19 surveillance.

Methods

Overview

Our application ontology was developed in 3 stages—stage 1: creating and testing our use case; stage 2: developing the COVID-19 surveillance ontology; and stage 3: external validation using a rapid Delphi consensus exercise. We classified this as an application ontology because the system crosses a range of domains to deliver specific goals. The data source was routine primary care data from the RCGP RSC sentinel network, combined with virology and serology sampling data from PHE.

Additionally, a practice dashboard and a practice liaison team helped ensure data quality [23]. Episode type, whether a case is a first or incident case or a follow-up is important for surveillance; while we can infer this from records it is better if it is collected as primary information [24].

Stage 1: Creating and Testing the Use Case

We created a testable narrative use case for COVID-19 surveillance, using previously described methods [25,26]. The primary actor was the RCGP RSC, the system it interacts with was the national response to the COVID-19 pandemic, and its outcomes entailed monitoring spread and effect of mitigation measures.

The use case has been progressively implemented in-pandemic. We report our implementation across the domains identified. As our ontology developed and formalized, post hoc checking was done to ensure extracts were ontology compliant.

Stage 2: Developing the COVID-19 Surveillance Ontology

We developed an application ontology to support extended surveillance using routine CMR data. The terminology and clinical understanding and response to COVID-19 were rapidly changing during the development period. The ontology has built-in flexibility to accommodate these and further changes.

We used our 3-step ontological process to identify codes to meet our requirements [12,21,22]:

- Step 1: the ontology layer; defines relevant COVID-19 surveillance concepts and may include exposure, investigations, diagnoses, or other “processes of care.” Part of our ontological process is to iterate whether cases identified are definite, probable, or possible, based on the specificity of the codes used (an approach developed in diabetes research [27]);
- Step 2: the coding layer; applies concepts of the ontology layer to the specific coding system used in the CMR. Individual codes are classified as having direct, partial, or no clear mapping to the criteria considered [28]. In this case, we extended this to exclude suspected cases where there was a subsequent negative test. Post hoc data validation was done largely via our practice liaison team. One member of the team was entirely dedicated to ensuring data quality providing anticipatory training and coding aids, and a responsive service;
- Step 3: the logical data extract model; systematically tests the codes identified to ensure that data outputs are consistent with study requirements.

We wanted our resource to be findable, accessible, interoperable, and reusable (FAIR) [29], so we used standard tools in its development, namely the Protégé ontology development environment [30] and Web Ontology Language (OWL) [31].

The scope of the ontology included:

- Demographic details, including age, gender, ethnicity, deprivation, rurality, and linking key identifiers;
- Recording of monitored conditions and key clinical features (ie, symptoms and signs);
- Relevant comorbidities and risk factors;
- Tests and test results (ie, COVID-19-specific and test results that might imply susceptibility or resilience);
- Key outcome measures including hospitalization, oxygen therapy, intensive care admission, and mortality.

Stage 3: External Evaluation of the Ontology

We carried out a rapid Delphi consensus exercise by inviting a panel (n=9) of international primary care clinicians and informaticians through the International Medical Informatics Association Primary Health Care Informatics working group and extended networks [32,33]. The consensus exercise consisted of 3 rounds:

1. We shared our initial ontology and requested panel members to inform us about additional concepts that were not present in the ontology but present in their clinical workflows. In order to facilitate rapid consensus, we used email correspondence for this stage.
2. We shared the revised ontology with panel members, who were asked to indicate their level of agreement, on a 5-point Likert scale, to statements related to the coverage of concepts and applicability of the ontology to their primary care system. This was delivered through an online survey

(see panel members and questions in [Multimedia Appendix 1](#)). Consensus was defined as $\geq 80\%$ agreement. Statements not meeting 80% agreement were modified according to the feedback provided by the expert panel and redistributed to panelists for round 3.

3. We conducted an online discussion to review and approve the final ontology.

Ethical Considerations

COVID-19 surveillance is carried out by RCGP RSC in collaboration with PHE, and approved under Regulation 3 of The Health Service (Control of Patient Information) Regulations 2002 by PHE's Caldicott Guardian [34]. No specific permissions were needed for our ontology development as no additional processing of data was required.

Results

Stage 1: Creating and Testing the Use Case

We developed a summary narrative use case ([Table 1](#)). The success scenarios listed are goals we want to achieve.

The success scenarios and extensions reflect the cross-domain activities within the use case. We list the outcomes across 5 domains: primary care, public health, virology, clinical research, and clinical informatics ([Table 2](#)). We implemented our ontology through practical activities across these domains.

Table 1. Summary narrative use case.

Variable	Description
Actor	<ul style="list-style-type: none"> Oxford Royal College of General Practitioners Research and Surveillance Centre
Scope	<ul style="list-style-type: none"> Delivery of COVID-19 surveillance and research
Level	<ul style="list-style-type: none"> Health care system wide
Stakeholders and interests	
Patients and public	<ul style="list-style-type: none"> Safe and timely guidance through the pandemic
General practices	<ul style="list-style-type: none"> Professional interest; payment; providing high-quality, evidence-based care
Public Health England	<ul style="list-style-type: none"> Need data to predict transmission Monitor the effectiveness of interventions
Royal College of General Practitioners	<ul style="list-style-type: none"> Care for/protect members Contribute to pandemic response
Primary care clinical trials unit	<ul style="list-style-type: none"> Data governance policies control which data can be viewed Recruit to trial to mitigate COVID-19
Precondition	<ul style="list-style-type: none"> Legal basis, permissions for data extracts, data extraction, and analytics capability within the network
Minimal guarantee	<ul style="list-style-type: none"> Delivery of data and analytics at prepandemic scale
Success guarantee	<ul style="list-style-type: none"> Larger network with high-quality data Outputs to meet changed requirements during the pandemic Authoritative source of primary care data, evidenced by academic publication
Main success scenario	<ul style="list-style-type: none"> High-quality primary care data, feedback to practices via customized dashboards Representative sampling of virology and serology by collecting the specified number of samples (900 virology, 1000 serology per week) Twice weekly data feeds to Public Health England to meet their data requirements National observatories and weekly return that represent the impact of COVID-19 Ensure that we fully recruit to the PRINCIPLE^a and other trials through the Oxford–RCGP RSC system High-quality publication of lessons from surveillance
Extensions	<ul style="list-style-type: none"> Trebling the number of virology practices (we have gone from 100 to 300 virology sampling practices, from 10 to 200 serology sampling practices) Adjusting to the effect of lockdowns on: <ul style="list-style-type: none"> Extending the network to over 1000 practices to support large-scale clinical trials, embedded in clinical practice; eg, recruitment into the PRINCIPLE trial Sampling all eligible patients due to the reduced number seen on surgery premises Postconvalescent serology; we will collect convalescent serology at 28 days from a wide range of practices Managing unforeseen problems: <ul style="list-style-type: none"> Refusal of some post offices to allow sample postage Postage delays Swab supply problems Piloting new methods of swab delivery to patients Add resilience to the surveillance system <ul style="list-style-type: none"> Human resilience - extending data team and support System resilience - direct feeds from major CMR^b suppliers Other studies: large numbers of study requests that need managing

^aPRINCIPLE: Platform Randomised Trial of Interventions Against COVID-19 in Older People.^bCMR: computerized medical record.

Table 2. Application use-case outcomes by domain.

Domain	Description	Outcomes
Primary care	<ul style="list-style-type: none"> COVID-19 Observatory - temporal and geographic surveillance COVID-19 dashboard - practice-level data quality 	<ul style="list-style-type: none"> Data quality feedback to practices Feedback from practices
Public health	<ul style="list-style-type: none"> COVID-19 - supplementary report Public health policy - containment measures 	<ul style="list-style-type: none"> Trends of community transmission after social distancing ends Estimates of COVID-19-related community morbidity and mortality
Virology	<ul style="list-style-type: none"> Swabbing - investigation <ul style="list-style-type: none"> Virology Serology 	<ul style="list-style-type: none"> Virologically confirmed incidence Representative collection of serology for sero-epidemiology Ordering stock control and swab and virology container supply
Clinical research	<ul style="list-style-type: none"> Recruitment to clinical trials 	<ul style="list-style-type: none"> Health outcomes: chest infections, hospitalization, intensive care unit, mechanical ventilation, oxygen therapy, and death
Clinical informatics	<ul style="list-style-type: none"> IG^a—legal basis, data sharing agreements, contracts Hardware and its resilience Semantic interoperability across domains 	<ul style="list-style-type: none"> Data quality, usability, FAQs^b—continuous improvement of our interface Adaptability with changing clinical knowledge Ontology with annotations to clinical terms/codes

^aIG: information governance.

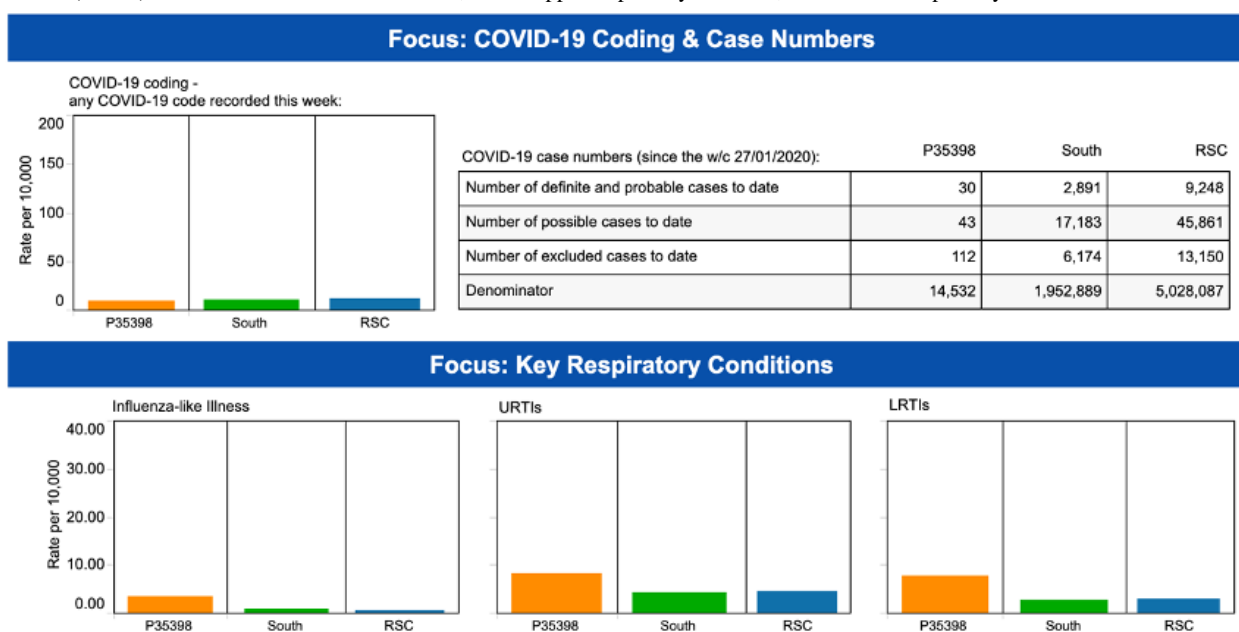
^bFAQ: frequently asked question.

Primary Care Domain: Data Quality and Feedback to General Practices (COVID-19 Dashboard)

Our COVID-19 dashboard presented weekly data on respiratory conditions to practices within the RCGP RSC sentinel network. Data were presented on COVID-19 incidence for the individual practice, and at the regional and national levels for reference,

along with rates of other respiratory infections (Figure 1). Postimplementation feedback had to keep pace with multiple data changes and different timetables of code releases between CMR system providers. It included constant updating of coding prompt cards [35]. It also required liaison with computer template developers to change design to incorporate episode type.

Figure 1. COVID-19 dashboard for each RCGP RSC network practice [36]. The column starting P35398 is that practice data; “South” is their region; RSC is the rate across the whole network. Dates are presented in the DD/MM/YYYY format throughout. RCGP RSC: Oxford Royal College of General Practitioners (RCGP) Research and Surveillance Centre; URTI: upper respiratory infection; LRTI: lower respiratory infection.

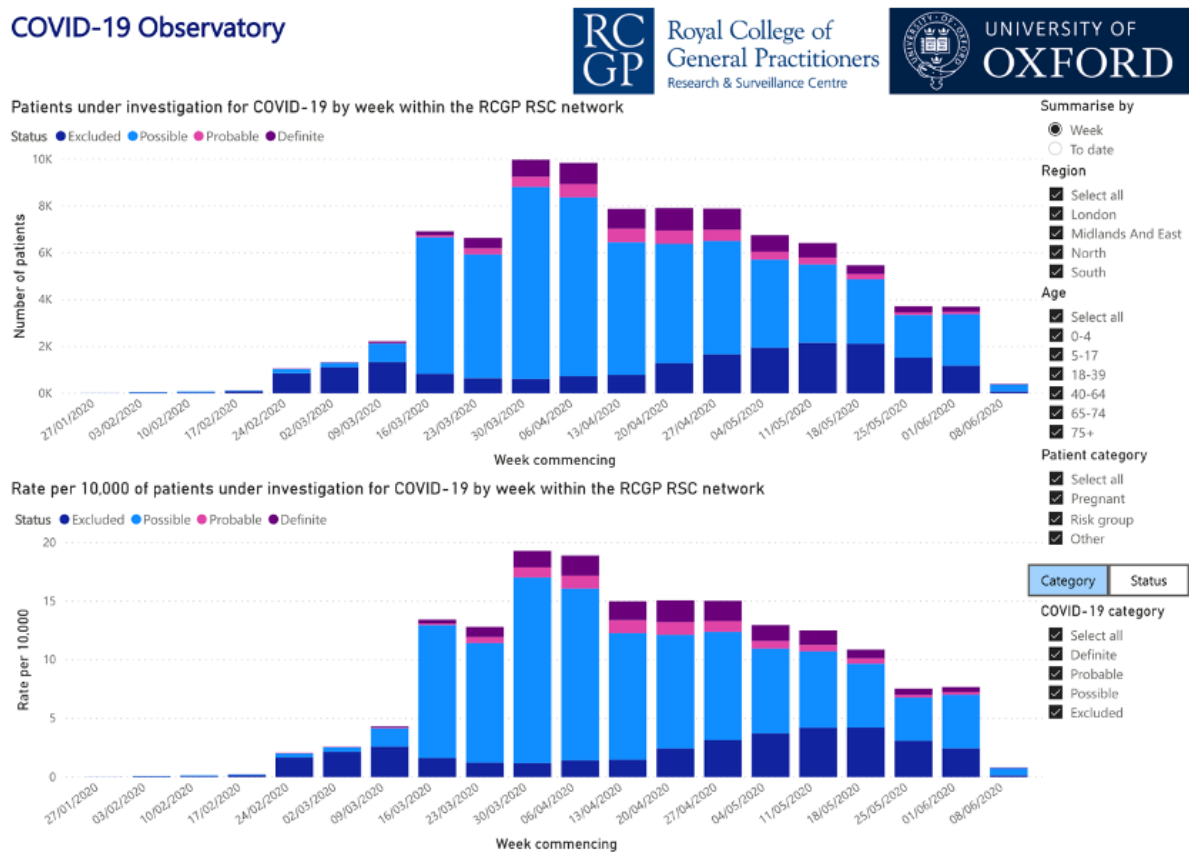


Public Health Domain: Data Visualization With COVID-19 Observatory

Our ontology ensured consistency between our classic weekly return, which now includes COVID-19 surveillance. In addition, we developed customized outputs for epidemiologists at PHE and an observatory to present data on the incidence of

COVID-19 across the network (Figure 2). This is based on coding described in the ontological layer and presents incidence rate per 10,000 cases of COVID-19. Up to the week commencing September 21, 2020, we have identified a total of 19,115 people with definite COVID-19, 5226 probable cases, and 74,293 people with possible COVID-19 within the RCGP RSC network (N=5,370,225).

Figure 2. Oxford RCGP RSC interactive COVID-19 observatory. Users can select the cumulative or week-by-week view of the data, and visualize data by age-band, region, risk group, and COVID-19 status (definite, probable, possible, and excluded) [37]. RCGP RSC: Oxford Royal College of General Practitioners Research and Surveillance Centre.



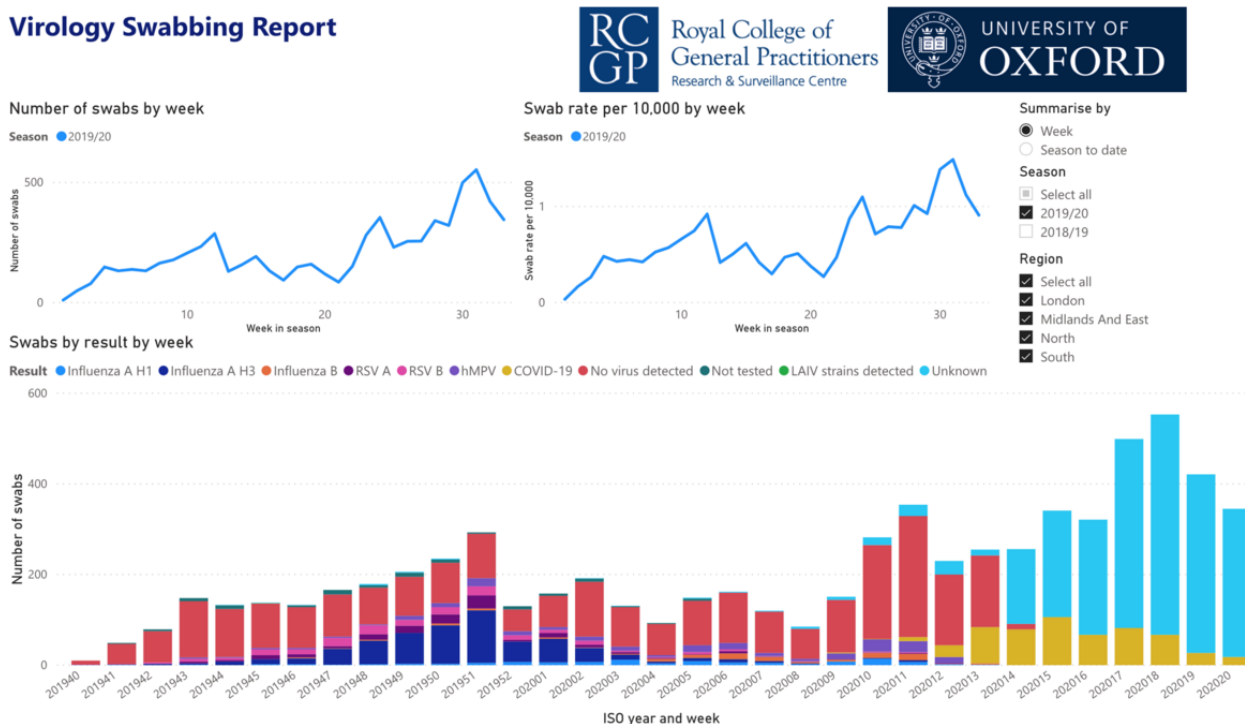
The biggest area of challenge was attribution of codes to certainty of diagnosis. We have had to evolve this with coding system changes (see Multimedia Appendix 1 for our final SNOMED CT [SNOMED Clinical Terms] concept list).

Virology Domain: Weekly Virologic Surveillance Reports

Similarly, our ontology drove the consistent extension of our virology reporting. Sound data structures have also been

important because the number of participating virology sampling practices trebled from 100 to 300 to provide more data. The weekly virology report provides a visualization of the absolute number and rate per 10,000 by week of the swabs taken, combined with the matched week from the previous year's figures for background context (Figure 3). There is a similar observatory for serology (included in Multimedia Appendix 1).

Figure 3. Oxford RCGP RSC interactive virology swabbing report. Users can look at the cumulative or weekly report or compare with the previous year, and look by infected organism or region. “Unknown” is used where no testing is done; currently, samples are only tested for COVID-19. RCGP RSC: Oxford Royal College of General Practitioners Research and Surveillance Centre; ISO: International Organization for Standardization.



Clinical Research Domain: Participation in Observational and Interventional Studies

The COVID-19 surveillance application ontology supported consistent reporting of findings in observational and interventional clinical research. We have a series of ongoing observational studies, the first of which has reported results [38]. The network is also supporting the PRINCIPLE (Platform Randomised Trial of Interventions Against COVID-19 in Older People) trial, a UK platform randomized controlled trial of interventions for COVID-19 in primary care. The study is assessing the effectiveness of trial treatments in reducing the need for hospital admission and death in patients with suspected COVID-19 infection aged ≥50 years with serious comorbidity, and aged ≥65 years with or without comorbidity [20]. To date, 830 practices have signed up, with 415 patients randomized; 468 (56.4%) of these are RCGP RSC practices, and they have recruited 342 (82.4%) of the included patients so far.

Clinical Informatics Domain: Creating the COVID-19 Ontology

The annotated application ontology was published on the BioPortal Ontology Repository [39] and will continue to be developed as our understanding of COVID-19 advances and new interventions (eg, vaccination) are introduced. The detail

of the ontological development is set out in stage 2 of our 3-step process.

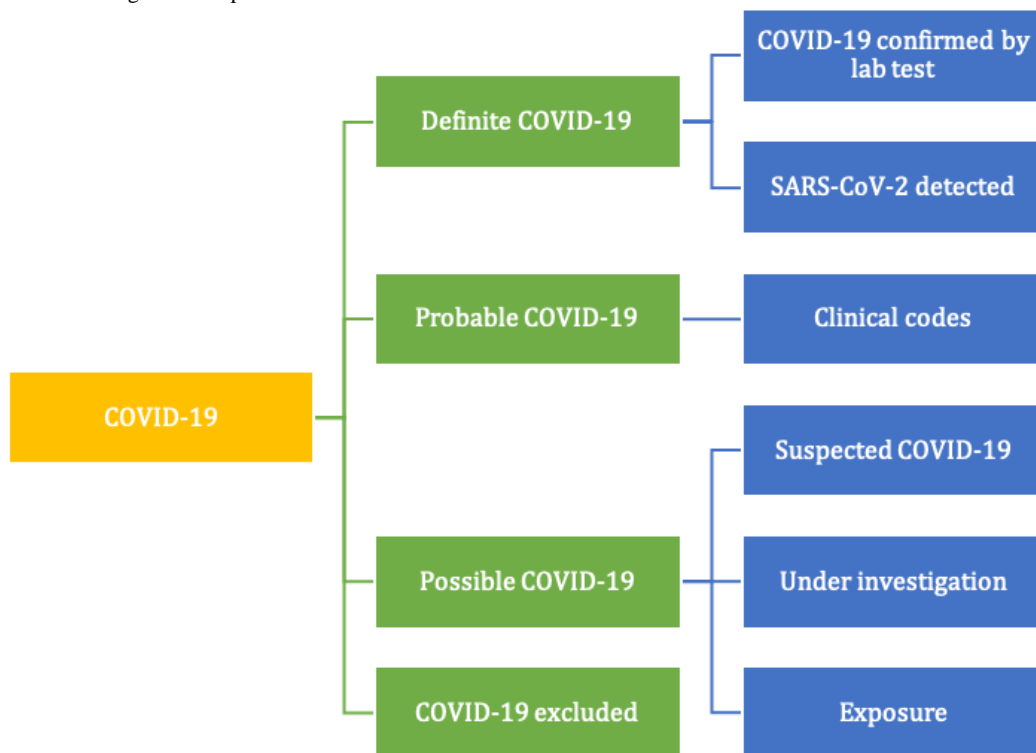
Stage 2: Developing the COVID-19 Surveillance Ontology

Step 1: Ontological Layer

We reviewed emerging case definitions of COVID-19 to identify key concepts used for case ascertainment and their relationships. Concepts included in the ontology were consistent with the WHO data dictionary for COVID-19 case-based reporting [40].

We have limited our presentation of results to the case definition of COVID-19. This has involved grouping concepts into: (1) definite, which include definitive codes for a laboratory-confirmed case of COVID-19; (2) probable, which included a clinical diagnosis of COVID-19 and use of out-of-date codes created during the previous SARS (severe acute respiratory syndrome) outbreak; (3) possible, which contains a range of coding alternatives related to suspected COVID-19 investigation but no result and exposure codes; and (4) excluded, where a test requested is reported as negative (this is demonstrated in Figure 4). At the individual level, the tests work hierarchically, with the most specific one driving the categorization.

Figure 4. Foundational ontological concepts used for COVID-19 surveillance.



Step 2: Coding Layer

We completed a dynamic process of mapping clinical terminology codes to concepts that emerged from our ontological layer (Table 3).

The National Health Service (NHS) uses the UK SNOMED CT system of coding, which is normally only updated twice yearly. In early February 2020, there were no clinical codes specific to COVID-19. Initially, CMR suppliers created 5 new system-wide local codes to support essential COVID-19-related recording within a week of being requested [11,19]. Subsequently, 2

emergency releases of novel COVID-19-related UK SNOMED CT codes were developed through a rapid consultation process conducted by the NHS Digital Information Representation Service [41], as greater clinical insight into COVID-19 and stability around nomenclature emerged. These UK SNOMED CT concepts were developed independently of international SNOMED CT terminology development; however, this open-source ontology can be mapped to international terms with ease. We iteratively annotated the ontological concepts with these stepwise-released COVID-19 SNOMED CT clinical concepts.

Table 3. Migration across SNOMED CT (SNOMED Clinical Terms) concepts released from February to May 2020.

Clinical concepts that should be coded in CMR ^{a,b}	Temporary codes ^c	Final SNOMED CT description
COVID-19 definite	<ul style="list-style-type: none"> Confirmed 2019 nCoV (Wuhan) infection OR Confirmed 2019 nCoV (novel coronavirus) infection 	<ul style="list-style-type: none"> COVID-19 confirmed by laboratory test SARS-CoV-2 (severe acute respiratory syndrome coronavirus 2) detected
COVID-19 probable	<ul style="list-style-type: none"> No specific codes 	<ul style="list-style-type: none"> COVID-19 COVID-19 confirmed by clinical diagnostic criteria
COVID-19 possible		
Exposure to infectious agent	<ul style="list-style-type: none"> Exposure to 2019 nCoV (Wuhan) infection OR Exposure to 2019 nCoV (novel coronavirus) infection 	<ul style="list-style-type: none"> Exposure to SARS-CoV-2 (severe acute respiratory syndrome coronavirus 2) infection
Suspected infection	<ul style="list-style-type: none"> Suspected 2019 nCoV (Wuhan) infection OR Suspected 2019 nCoV (novel coronavirus) infection 	<ul style="list-style-type: none"> Suspected COVID-19
Test for infectious agent offered or taken	<ul style="list-style-type: none"> No specific codes 	<ul style="list-style-type: none"> Swab for SARS-CoV-2 (severe acute respiratory syndrome coronavirus 2) taken by health care professional Self-taken swab for SARS-CoV-2 (severe acute respiratory syndrome coronavirus 2) offered Self-taken swab for SARS-CoV-2 (severe acute respiratory syndrome coronavirus 2) completed
	<ul style="list-style-type: none"> Tested for 2019 nCoV (Wuhan) infection OR Tested for 2019 nCoV (novel coronavirus) infection 	__ ^d
COVID-19 excluded	<ul style="list-style-type: none"> Excluded 2019 nCoV (Wuhan) infection OR Excluded 2019 nCoV (novel coronavirus) infection 	<ul style="list-style-type: none"> COVID-19 excluded COVID-19 excluded by laboratory test SARS-CoV-2 (severe acute respiratory syndrome coronavirus 2) not detected

^aCMR: computerized medical record.

^bFrom ontological layer.

^cUsed until replacement with SARS-CoV-2/COVID-19 concepts.

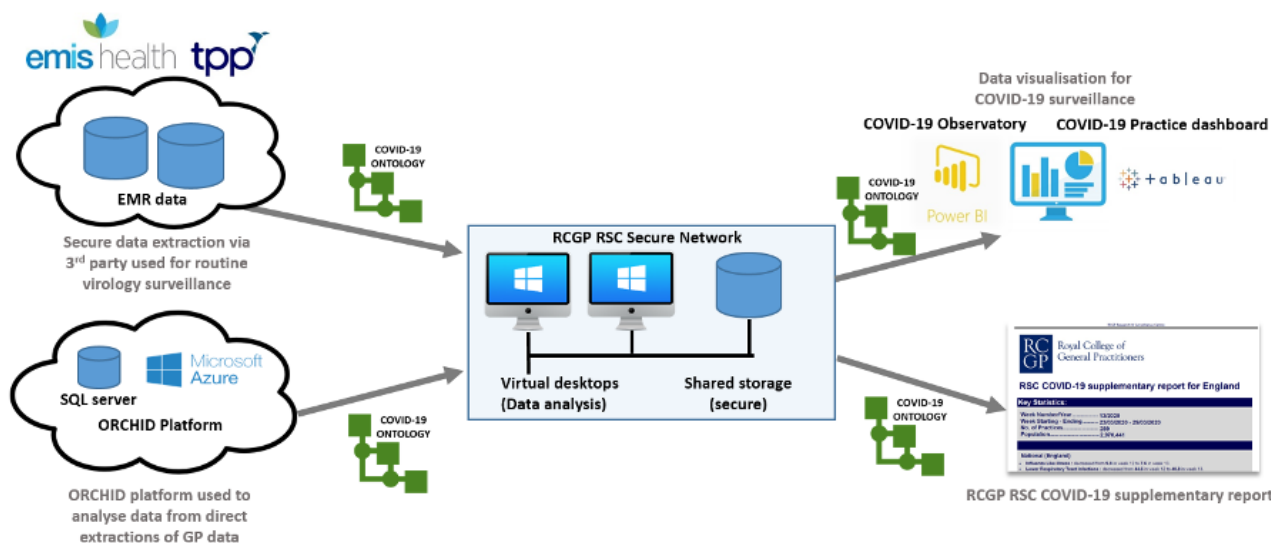
^dNot applicable.

Step 3: Logical Data Extract Layer

We incorporated the annotated ontology into the routine surveillance platform of the RCGP RSC data. The ontology identified various states of COVID-19 diagnosis in the incoming data feeds used for surveillance. We conducted a week-by-week

analysis of incoming data modifying our outputs to take account of supplier-specific changes in reporting. We are planning for cloud-based extracts and customized extracts from individual CMR vendors; to do this we are creating an Oxford RCGP Clinical Informatics Digital Hub (ORCHID) (Figure 5) [42].

Figure 5. Use of the COVID-19 surveillance ontology across the RCGP RSC processes to achieve semantic consistency in data extraction, visualizations, and surveillance reports. EMR: electronic medical record; GP: general practitioner; ORCHID: Oxford RCGP Clinical Informatics Digital Hub; RCGP RSC: Oxford Royal College of General Practitioners Research and Surveillance Centre; SQL: Structured Query Language.



External Evaluation of the Ontology

While we obtained a good consensus in our Delphi exercise, there was important learning and priorities flagged for development. Consensus was obtained for 7 out of 8 (87.5%) of the statements related to coverage of concepts under the upper level headings of the COVID-19 ontology. All panel members

except one agreed with statements relating to the applicability of the ontology for case finding activities in their local primary care setting (Table 4). Input from panel members guided expansion of the concepts related to statements not reaching consensus, and this was reviewed by panel members in round 3 of the Delphi exercise.

Table 4. Number of responses and % agreement (strongly agree/agree) to statements relating to the applicability of the ontology for case finding activities in panel members’ local primary care setting.

Statement	Strongly disagree, n	Disagree, n	Neither agree or disagree, n	Agree, n	Strongly agree, n	% Agreement
Please indicate your level of agreement with the coverage of concepts given under each upper level heading of the COVID-19 surveillance ontology.						
Symptoms and signs	0	1	0	3	5	88.9
Past medical history/at-risk conditions	0	0	3	2	4	66.7
Exposure	0	0	0	2	7	100
Investigations	0	0	0	5	4	100
COVID-19 case status	0	0	0	1	8	100
Interventions	0	1	0	3	5	88.9
Process of care	0	0	1	1	7	88.9
Outcomes	0	0	0	5	4	100
The COVID-19 ontology in its current format is suitable for COVID-19 case ascertainment in my local primary care setting.	0	0	1	5	3	88.9

Softer important discussion points emerged; for example, our symptom collection is relatively poorly developed and that there remains uncertainty about risk and protective factors. There was strong feeling among one expert that vaccination and exposures should be part of the ontology; these were subsequently added.

Discussion

Principal Findings

We rapidly developed an application ontology in-pandemic to support extended surveillance and research activities across the 5 clinical and informatics domains described in our use case. This application ontology has provided a framework, which we

have used to help ensure the reliability and consistency of our outputs at a time of change. This iterative ontological approach is flexible and robust enough to match the pace and direction of the evolving clinical landscape of COVID-19.

The focus of our work has been on case identification and associated test results, as these are the foundations on which epidemiological and interventional studies are based. We felt it appropriate to flag the certainty with which a diagnosis is made. We have already used this ontology in observational and interventional studies [20,38].

The separation of the coding layer from the ontological (conceptual) layer allows surveillance to be resilient while new case definitions and clinical codes are added to general practice CMR systems. This approach ensures transparency in case definitions used for reporting and facilitates clear communication by allowing clinicians, database developers (involved in extracting data from practices' data sources), and practice liaison officers (who advise practices about data recording best practices) to maintain consistency within an organization.

This application ontology could easily and rapidly be adapted for COVID-19 surveillance and clinical research in various other countries and health care networks. As the COVID-19 pandemic continues, there is enormous global pressure on health care systems to understand trends in incidence rates and conduct high-quality research; this ontology is open-source and can be mapped onto local clinical coding systems to permit consistency in analyses.

Comparison With Previous Literature

To our knowledge, this is the first time that a systematic ontological approach has been developed in-pandemic for extended disease surveillance, using structured routine clinical data. This application ontology aligns with previous clinical informatics literature on application ontology engineering and validation through the testable use-case approach [43,44].

There are other pandemic surveillance systems that look at open-source, unstructured data, such as media reports and clusters of symptom-related internet searches, extracting information of epidemiological relevance [45]. Examples of such systems include BioCaster [46], the Global Public Health Intelligence Network [47], ProMed [48], and HealthMap [49]. The latter three systems are working under the WHO collaborative, the Epidemic Intelligence from Open Sources initiative, which played a role in the identification of the COVID-19 outbreak from early media reports from China in December 2019 [50]. Some of the event-based pandemic surveillance systems have published ontological foundations in the public health and surveillance domains [46,51,52]. While useful for providing supplementary information to epidemiologists on the emergence of an outbreak in real time, these knowledge representations do not specifically address the types of information described in clinical data, such as

presenting complaint, comorbidities, virology, or health outcomes.

There are very limited studies of data platforms' performance within integrated clinical surveillance systems [45]. The lack of accurate and available data to underpin epidemic forecasting in emerging outbreaks has been highlighted [53].

We found no literature using an ontological approach for COVID-19 surveillance. There are domain ontologies related to the coronavirus published on BioPortal. The first focuses on the wider *Coronaviridae* family and their biochemical and microbiological properties [54], while the second was developed to provide semantic assistance for clinical research form completion [55]. None were designed to integrate the various clinical data streams necessary to carry out COVID-19 surveillance.

Strengths and Limitations

The 3-step iterative ontological process that we have implemented has proven to be suitably flexible to cope with the changes in COVID-19 terminology and CMR system codes. A further strength was the implementation and deployment of this ontology, considering the FAIR guiding principles [29]. The ontology is discoverable and accessible on the BioPortal ontology repository. This application ontology, built using best practices around defining and testing a use case, is inherently interoperable and reusable [29]. In the absence of a gold-standard infectious disease surveillance ontology, we believe our attempts at achieving a degree of consensus and external validity from a range of international experts in the field of clinical informatics and primary care as a major strength of the current study. While the Delphi panel size was relatively small and a limitation, we purposefully selected panel members from a range of countries with varied clinical coding systems.

We focused on case finding and results; we now need to turn our attention to presenting symptoms, particularly looking to focus on those that may be of prognostic value and emerging treatments including vaccination. Our ontology as currently run will classify false positive lab results incorrectly, and we recognize this is a limitation that should be noted by users. Additional limitations were its development in a single sentinel system and that it was not developed ready to integrate into a common data model [56].

Conclusions

We have created a COVID-19 application ontology, with strengths that include its speed of development, being openly shared via BioPortal, and its adaptability. The limitations are its development in a single sentinel network and its current limited focus. The ontology should make conclusions based on primary care sentinel data more transparent and facilitate pooled analyses in COVID-19 surveillance and research. We welcome any requests for information on applying our COVID-19 surveillance application ontology to other health care settings, both domestically and internationally.

Acknowledgments

We thank the practices and patients of RCGP RSC, who allowed their pseudonymized clinical medical records to be used for this work. We would also like to acknowledge the members of the Primary Health Care Informatics Working Group of the International Medical Informatics Association for their contribution in validating the ontology. Funding for this research was provided by Public Health England / Wellcome.

Authors' Contributions

SdL conceived the need for this ontology with important input from HL, JW, DE, and DM. DM and HL wrote an initial draft of the manuscript, and SdL produced the first complete manuscript. All authors contributed to the scope of the ontology, contributed comments, and read and approved the final version.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Supplementary tables and figures.

[[DOCX File , 473 KB - publichealth_v6i4e21434_app1.docx](#)]

References

1. Lipsitz LA. Understanding health care as a complex system: the foundation for unintended consequences. *JAMA* 2012 Jul 18;308(3):243-244 [FREE Full text] [doi: [10.1001/jama.2012.7551](https://doi.org/10.1001/jama.2012.7551)] [Medline: [22797640](https://pubmed.ncbi.nlm.nih.gov/22797640/)]
2. Sturmberg J, Lanham HJ. Understanding health care delivery as a complex system: achieving best possible health outcomes for individuals and communities by focusing on interdependencies. *J Eval Clin Pract* 2014 Dec 05;20(6):1005-1009. [doi: [10.1111/jep.12142](https://doi.org/10.1111/jep.12142)] [Medline: [24797788](https://pubmed.ncbi.nlm.nih.gov/24797788/)]
3. Wang C, Horby PW, Hayden FG, Gao GF. A novel coronavirus outbreak of global health concern. *The Lancet* 2020 Feb 15;395(10223):470-473 [FREE Full text] [doi: [10.1016/S0140-6736\(20\)30185-9](https://doi.org/10.1016/S0140-6736(20)30185-9)] [Medline: [31986257](https://pubmed.ncbi.nlm.nih.gov/31986257/)]
4. Novel Coronavirus(2019-nCoV) Situation Report - 10. World Health Organization. 2020 Jan 30. URL: https://www.who.int/docs/default-source/coronaviruse/situation-reports/20200130-sitrep-10-ncov.pdf?sfvrsn=d0b2e480_2 [accessed 2020-05-11]
5. Gorbalenya A. Severe acute respiratory syndrome-related coronavirus: The species and its viruses – a statement of the Coronavirus Study Group. bioRxiv Preprint posted online February 11, 2020. [doi: [10.1101/2020.02.07.937862](https://doi.org/10.1101/2020.02.07.937862)]
6. Novel Coronavirus (2019-nCoV) Situation Report - 22. World Health Organization. 2020 Feb 11. URL: <https://www.who.int/docs/default-source/coronaviruse/situation-reports/20200211-sitrep-22-ncov.pdf> [accessed 2020-05-11]
7. Huang C, Wang Y, Li X, Ren L, Zhao J, Hu Y, et al. Clinical features of patients infected with 2019 novel coronavirus in Wuhan, China. *Lancet* 2020 Feb 15;395(10223):497-506 [FREE Full text] [doi: [10.1016/S0140-6736\(20\)30183-5](https://doi.org/10.1016/S0140-6736(20)30183-5)] [Medline: [31986264](https://pubmed.ncbi.nlm.nih.gov/31986264/)]
8. Giacomelli A, Pezzati L, Conti F, Bernacchia D, Siano M, Oreni L, et al. Self-reported Olfactory and Taste Disorders in Patients With Severe Acute Respiratory Coronavirus 2 Infection: A Cross-sectional Study. *Clin Infect Dis* 2020 Jul 28;71(15):889-890 [FREE Full text] [doi: [10.1093/cid/ciaa330](https://doi.org/10.1093/cid/ciaa330)] [Medline: [32215618](https://pubmed.ncbi.nlm.nih.gov/32215618/)]
9. Baud D, Qi X, Nielsen-Saines K, Musso D, Pomar L, Favre G. Real estimates of mortality following COVID-19 infection. *Lancet Infect Dis* 2020 Jul;20(7):773 [FREE Full text] [doi: [10.1016/S1473-3099\(20\)30195-X](https://doi.org/10.1016/S1473-3099(20)30195-X)] [Medline: [32171390](https://pubmed.ncbi.nlm.nih.gov/32171390/)]
10. Verity R, Okell LC, Dorigatti I, Winskill P, Whittaker C, Imai N, et al. Estimates of the severity of coronavirus disease 2019: a model-based analysis. *The Lancet Infectious Diseases* 2020 Jun;20(6):669-677. [doi: [10.1016/S1473-3099\(20\)30243-7](https://doi.org/10.1016/S1473-3099(20)30243-7)]
11. de Lusignan S, Williams J. To monitor the COVID-19 pandemic we need better quality primary care data. *BJGP Open* 2020;4(2) [FREE Full text] [doi: [10.3399/bjgpopen20X101070](https://doi.org/10.3399/bjgpopen20X101070)] [Medline: [32295793](https://pubmed.ncbi.nlm.nih.gov/32295793/)]
12. de Lusignan S. In this issue: Ontologies a key concept in informatics and key for open definitions of cases, exposures, and outcome measures. *J Innov Health Inform* 2015 Jul 10;22(2):170 [FREE Full text] [doi: [10.14236/jhi.v22i2.170](https://doi.org/10.14236/jhi.v22i2.170)] [Medline: [26245238](https://pubmed.ncbi.nlm.nih.gov/26245238/)]
13. Musen MA. Domain Ontologies in Software Engineering: Use of Protégé with the EON Architecture. *Methods Inf Med* 2018 Feb 15;37(04/05):540-550. [doi: [10.1055/s-0038-1634543](https://doi.org/10.1055/s-0038-1634543)]
14. Malone J, Parkinson H. Reference and Application Ontologies. *Ontogenesis*. 2010. URL: <http://ontogenesis.knowledgeblog.org/295/> [accessed 2020-05-11]
15. Kumarapeli P, De Lusignan S, Ellis T, Jones B. Using Unified Modelling Language (UML) as a process-modelling technique for clinical-research process improvement. *Med Inform Internet Med* 2007 Mar 12;32(1):51-64. [doi: [10.1080/14639230601097705](https://doi.org/10.1080/14639230601097705)] [Medline: [17365645](https://pubmed.ncbi.nlm.nih.gov/17365645/)]

16. Correa A, Hinton W, McGovern A, van VJ, Yonova I, Jones S, et al. Royal College of General Practitioners Research and Surveillance Centre (RCGP RSC) sentinel network: a cohort profile. *BMJ Open* 2016 Apr 20;6(4):e011092 [FREE Full text] [doi: [10.1136/bmjopen-2016-011092](https://doi.org/10.1136/bmjopen-2016-011092)] [Medline: [27098827](https://pubmed.ncbi.nlm.nih.gov/27098827/)]
17. de Lusignan S, Correa A, Smith GE, Yonova I, Pebody R, Ferreira F, et al. RCGP Research and Surveillance Centre: 50 years' surveillance of influenza, infections, and respiratory conditions. *Br J Gen Pract* 2017 Sep 29;67(663):440-441. [doi: [10.3399/bjgp17x692645](https://doi.org/10.3399/bjgp17x692645)]
18. Pebody R, Warburton F, Ellis J, Andrews N, Potts A, Cottrell S, et al. Effectiveness of seasonal influenza vaccine for adults and children in preventing laboratory-confirmed influenza in primary care in the United Kingdom: 2015/16 end-of-season results. *Euro Surveill* 2016 Sep 22;21(38) [FREE Full text] [doi: [10.2807/1560-7917.ES.2016.21.38.30348](https://doi.org/10.2807/1560-7917.ES.2016.21.38.30348)] [Medline: [27684603](https://pubmed.ncbi.nlm.nih.gov/27684603/)]
19. de Lusignan S, Lopez Bernal J, Zambon M, Akinyemi O, Amirthalingam G, Andrews N, et al. Emergence of a Novel Coronavirus (COVID-19): Protocol for Extending Surveillance Used by the Royal College of General Practitioners Research and Surveillance Centre and Public Health England. *JMIR Public Health Surveill* 2020 Apr 02;6(2):e18606 [FREE Full text] [doi: [10.2196/18606](https://doi.org/10.2196/18606)] [Medline: [32240095](https://pubmed.ncbi.nlm.nih.gov/32240095/)]
20. Butler C. PRINCIPLE: A trial evaluating treatments for suspected COVID-19 in people aged 50 years and above with pre-existing conditions and those aged 65 years and above. *ISRCTN Registry* 2020. [doi: [10.1186/ISRCTN86534580](https://doi.org/10.1186/ISRCTN86534580)]
21. Cole NI, Liyanage H, Suckling RJ, Swift PA, Gallagher H, Byford R, et al. An ontological approach to identifying cases of chronic kidney disease from routine primary care data: a cross-sectional study. *BMC Nephrol* 2018 Apr 10;19(1):85 [FREE Full text] [doi: [10.1186/s12882-018-0882-9](https://doi.org/10.1186/s12882-018-0882-9)] [Medline: [29636024](https://pubmed.ncbi.nlm.nih.gov/29636024/)]
22. Liyanage H, Williams J, Byford R, de Lusignan S. Ontology to identify pregnant women in electronic health records: primary care sentinel network database study. *BMJ Health Care Inform* 2019 Jul;26(1) [FREE Full text] [doi: [10.1136/bmjhci-2019-100013](https://doi.org/10.1136/bmjhci-2019-100013)] [Medline: [31272998](https://pubmed.ncbi.nlm.nih.gov/31272998/)]
23. Smith S, Morbey R, de Lusignan S, Pebody R, Smith G, Elliot A. Investigating regional variation of respiratory infections in a general practice syndromic surveillance system. *J Public Health (Oxf)* 2020 Feb 02. [doi: [10.1093/pubmed/fdaa014](https://doi.org/10.1093/pubmed/fdaa014)] [Medline: [32009178](https://pubmed.ncbi.nlm.nih.gov/32009178/)]
24. Smith N, Livina V, Byford R, Ferreira F, Yonova I, De LS. Automated differentiation of incident and prevalent cases in primary care computerised medical records (CMR). In: *Studies in Health Technology and Informatics*. Amsterdam: IOS Press; 2018:151-155.
25. Cockburn A. *Writing effective use cases*. Boston: Addison-Wesley Professional; 2000.
26. Liyanage H, de Lusignan S, Liaw S, Kuziemyky CE, Mold F, Krause P, et al. Big Data Usage Patterns in the Health Care Domain: A Use Case Driven Approach Applied to the Assessment of Vaccination Benefits and Risks. Contribution of the IMIA Primary Healthcare Working Group. *Yearb Med Inform* 2014 Aug 15;9:27-35 [FREE Full text] [doi: [10.15265/IY-2014-0016](https://doi.org/10.15265/IY-2014-0016)] [Medline: [25123718](https://pubmed.ncbi.nlm.nih.gov/25123718/)]
27. de Lusignan S, Khunti K, Belsey J, Hattersley A, van Vlymen J, Gallagher H, et al. A method of identifying and correcting miscoding, misclassification and misdiagnosis in diabetes: a pilot and validation study of routinely collected data. *Diabet Med* 2010 Feb;27(2):203-209. [doi: [10.1111/j.1464-5491.2009.02917.x](https://doi.org/10.1111/j.1464-5491.2009.02917.x)] [Medline: [20546265](https://pubmed.ncbi.nlm.nih.gov/20546265/)]
28. Rollason W, Khunti K, de Lusignan S. Variation in the recording of diabetes diagnostic data in primary care computer systems: implications for the quality of care. *Inform Prim Care* 2009 Jun 01;17(2):113-119 [FREE Full text] [doi: [10.14236/jhi.v17i2.723](https://doi.org/10.14236/jhi.v17i2.723)] [Medline: [19807953](https://pubmed.ncbi.nlm.nih.gov/19807953/)]
29. Wilkinson MD, Dumontier M, Aalbersberg IJ, Appleton G, Axton M, Baak A, et al. The FAIR Guiding Principles for scientific data management and stewardship. *Sci Data* 2016 Mar 15;3(1):160018 [FREE Full text] [doi: [10.1038/sdata.2016.18](https://doi.org/10.1038/sdata.2016.18)] [Medline: [26978244](https://pubmed.ncbi.nlm.nih.gov/26978244/)]
30. Musen MA, The Protégé Project. The Protégé Project: A Look Back and a Look Forward. *AI Matters* 2015 Jun;1(4):4-12 [FREE Full text] [doi: [10.1145/2757001.2757003](https://doi.org/10.1145/2757001.2757003)] [Medline: [27239556](https://pubmed.ncbi.nlm.nih.gov/27239556/)]
31. McGuinness D, van Harmelen F. OWL Web Ontology Language Overview: W3C Recommendation. W3C. URL: <https://www.w3.org/TR/owl-features/> [accessed 2020-11-09]
32. Liaw S, Liyanage H, Kuziemyky C, Terry AL, Schreiber R, Jonnagaddala J, et al. Ethical Use of Electronic Health Record Data and Artificial Intelligence: Recommendations of the Primary Care Informatics Working Group of the International Medical Informatics Association. *Yearb Med Inform* 2020 Aug 17;29(1):51-57 [FREE Full text] [doi: [10.1055/s-0040-1701980](https://doi.org/10.1055/s-0040-1701980)] [Medline: [32303098](https://pubmed.ncbi.nlm.nih.gov/32303098/)]
33. Liyanage H, Liaw S, Jonnagaddala J, Schreiber R, Kuziemyky C, Terry AL, et al. Artificial Intelligence in Primary Health Care: Perceptions, Issues, and Challenges. *Yearb Med Inform* 2019 Aug 25;28(1):41-46. [doi: [10.1055/s-0039-1677901](https://doi.org/10.1055/s-0039-1677901)] [Medline: [31022751](https://pubmed.ncbi.nlm.nih.gov/31022751/)]
34. Taylor MJ. Legal bases for disclosing confidential patient information for public health: Distinguishing between health protection and health improvement. *Med Law Rev* 2015 May 20;23(3):348-374 [FREE Full text] [doi: [10.1093/medlaw/fwv018](https://doi.org/10.1093/medlaw/fwv018)] [Medline: [25995294](https://pubmed.ncbi.nlm.nih.gov/25995294/)]
35. RCGP RSC COVID-19 Surveillance. RCGP RSC. 2020. URL: <https://clininf.eu/index.php/cov-19/> [accessed 2020-06-13]
36. RCGP RSC COVID-19 Practice-Level Dashboard. RCGP RSC. 2020. URL: <https://clininf.eu/index.php/covid/> [accessed 2020-06-13]

37. COVID-19 Observatory. RCGP RSC. 2020. URL: <https://tinyurl.com/yy6gnua2> [accessed 2020-03-31]
38. de Lusignan S, Dorward J, Correa A, Jones N, Akinyemi O, Amirthalingam G, et al. Risk factors for SARS-CoV-2 among patients in the Oxford Royal College of General Practitioners Research and Surveillance Centre primary care network: a cross-sectional study. *The Lancet Infectious Diseases* 2020 Sep;20(9):1034-1042. [doi: [10.1016/s1473-3099\(20\)30371-6](https://doi.org/10.1016/s1473-3099(20)30371-6)]
39. Liyanage H, de LS, Williams J. COVID-19 Surveillance Ontology. *BioPortal*. 2020. URL: <https://bioportal.bioontology.org/ontologies/COVID19> [accessed 2020-05-04]
40. Global surveillance for COVID-19 caused by human infection with COVID-19 virus: Interim guidance. World Health Organization. 2020 Mar 20. URL: <https://apps.who.int/iris/bitstream/handle/10665/331506/WHO-2019-nCoV-SurveillanceGuidance-2020.6-eng.pdf> [accessed 2020-03-30]
41. Clinical guidance on COVID-19 SNOMED codes. NHS Digital. 2020. URL: <https://theprsb.org/standards/covid-19snomedcodes/> [accessed 2020-04-10]
42. de Lusignan S, Jones N, Dorward J, Byford R, Liyanage H, Briggs J, et al. The Oxford Royal College of General Practitioners Clinical Informatics Digital Hub: Protocol to Develop Extended COVID-19 Surveillance and Trial Platforms. *JMIR Public Health Surveill* 2020 Jul 02;6(3):e19773 [FREE Full text] [doi: [10.2196/19773](https://doi.org/10.2196/19773)] [Medline: [32484782](https://pubmed.ncbi.nlm.nih.gov/32484782/)]
43. Malone J, Holloway E, Adamusiak T, Kapushesky M, Zheng J, Kolesnikov N, et al. Modeling sample variables with an Experimental Factor Ontology. *Bioinformatics* 2010 Apr 15;26(8):1112-1118 [FREE Full text] [doi: [10.1093/bioinformatics/btq099](https://doi.org/10.1093/bioinformatics/btq099)] [Medline: [20200009](https://pubmed.ncbi.nlm.nih.gov/20200009/)]
44. Doing-Harris KM, Zeng-Treitler Q. Computer-assisted update of a consumer health vocabulary through mining of social network data. *J Med Internet Res* 2011 May 17;13(2):e37 [FREE Full text] [doi: [10.2196/jmir.1636](https://doi.org/10.2196/jmir.1636)] [Medline: [21586386](https://pubmed.ncbi.nlm.nih.gov/21586386/)]
45. Velasco E, Agheneza T, Denecke K, Kirchner G, Eckmanns T. Social media and internet-based data in global systems for public health surveillance: a systematic review. *Milbank Q* 2014 Mar 06;92(1):7-33. [doi: [10.1111/1468-0009.12038](https://doi.org/10.1111/1468-0009.12038)] [Medline: [24597553](https://pubmed.ncbi.nlm.nih.gov/24597553/)]
46. Collier N, Doan S, Kawazoe A, Goodwin RM, Conway M, Tateno Y, et al. BioCaster: detecting public health rumors with a Web-based text mining system. *Bioinformatics* 2008 Dec 15;24(24):2940-2941 [FREE Full text] [doi: [10.1093/bioinformatics/btn534](https://doi.org/10.1093/bioinformatics/btn534)] [Medline: [18922806](https://pubmed.ncbi.nlm.nih.gov/18922806/)]
47. Dion M, AbdelMalik P, Mawudeku A. Big Data and the Global Public Health Intelligence Network (GPHIN). *Can Commun Dis Rep* 2015 Sep 03;41(9):209-214 [FREE Full text] [doi: [10.14745/ccdr.v41i09a02](https://doi.org/10.14745/ccdr.v41i09a02)] [Medline: [29769954](https://pubmed.ncbi.nlm.nih.gov/29769954/)]
48. Yu VL, Madoff LC. ProMED-mail: an early warning system for emerging diseases. *Clin Infect Dis* 2004 Jul 15;39(2):227-232 [FREE Full text] [doi: [10.1086/422003](https://doi.org/10.1086/422003)] [Medline: [15307032](https://pubmed.ncbi.nlm.nih.gov/15307032/)]
49. Freifeld CC, Mandl KD, Reis BY, Brownstein JS. HealthMap: Global Infectious Disease Monitoring through Automated Classification and Visualization of Internet Media Reports. *Journal of the American Medical Informatics Association* 2008 Mar 01;15(2):150-157. [doi: [10.1197/jamia.m2544](https://doi.org/10.1197/jamia.m2544)]
50. Epidemic Intelligence from Open Sources (EIOS). World Health Organization. 2020. URL: <https://www.who.int/eios> [accessed 2020-04-03]
51. Okhmatovskaia A, Chapman WW, Collier N, Espino J, Buckeridge DL. SSO: The Syndromic Surveillance Ontology. The National Center for Biomedical Ontology. 2009. URL: <https://ncbo.bioontology.org/sites/default/files/SSO.pdf> [accessed 2020-04-03]
52. Crubézy M, O'Connor M, Buckeridge D, Pincus Z, Musen M. Ontology-Centered Syndromic Surveillance for Bioterrorism. *IEEE Intell. Syst* 2005 Sep;20(5):26-35. [doi: [10.1109/mis.2005.91](https://doi.org/10.1109/mis.2005.91)]
53. Buckee C. Improving epidemic surveillance and response: big data is dead, long live big data. *The Lancet Digital Health* 2020 May;2(5):e218-e220. [doi: [10.1016/s2589-7500\(20\)30059-5](https://doi.org/10.1016/s2589-7500(20)30059-5)]
54. He Y. Coronavirus Infectious Disease Ontology. *BioPortal*. 2020. URL: <http://bioportal.bioontology.org/ontologies/CIDO> [accessed 2020-04-14]
55. Bonino L. WHO COVID-19 Rapid Version CRF semantic data model. *BioPortal*. 2020. URL: <https://bioportal.bioontology.org/ontologies/COVIDCRFRAPID?p=summary> [accessed 2020-04-23]
56. Liyanage H, Liaw S, Jonnagaddala J, Hinton W, de Lusignan S. Common Data Models (CDMs) to Enhance International Big Data Analytics: A Diabetes Use Case to Compare Three CDMs. *Stud Health Technol Inform* 2018;255:60-64. [Medline: [30306907](https://pubmed.ncbi.nlm.nih.gov/30306907/)]

Abbreviations

- CMR:** computerized medical record
- FAIR:** findable, accessible, interoperable, and reusable
- NHS:** National Health Service
- OWL:** Web Ontology Language
- PHE:** Public Health England
- PRINCIPLE:** Platform Randomised Trial of Interventions Against COVID-19 in Older People
- RCGP:** Oxford Royal College of General Practitioners
- RSC:** Research and Surveillance Centre

SARS: severe acute respiratory syndrome
SNOMED CT: SNOMED Clinical Terms
ORCHID: Oxford RCGP Clinical Informatics Digital Hub

Edited by T Sanchez; submitted 01.07.20; peer-reviewed by PSS Lee, J Aarts; comments to author 22.09.20; revised version received 02.10.20; accepted 02.10.20; published 17.11.20.

Please cite as:

de Lusignan S, Liyanage H, McGagh D, Jani BD, Bauwens J, Byford R, Evans D, Fahey T, Greenhalgh T, Jones N, Mair FS, Okusi C, Parimalanathan V, Pell JP, Sherlock J, Tamburis O, Tripathy M, Ferreira F, Williams J, Hobbs FDR

COVID-19 Surveillance in a Primary Care Sentinel Network: In-Pandemic Development of an Application Ontology

JMIR Public Health Surveill 2020;6(4):e21434

URL: <http://publichealth.jmir.org/2020/4/e21434/>

doi: [10.2196/21434](https://doi.org/10.2196/21434)

PMID: [33112762](https://pubmed.ncbi.nlm.nih.gov/33112762/)

©Simon de Lusignan, Harshana Liyanage, Dylan McGagh, Bhautesh Dinesh Jani, Jorgen Bauwens, Rachel Byford, Dai Evans, Tom Fahey, Trisha Greenhalgh, Nicholas Jones, Frances S Mair, Cecilia Okusi, Vaishnavi Parimalanathan, Jill P Pell, Julian Sherlock, Oscar Tamburis, Manasa Tripathy, Filipa Ferreira, John Williams, F D Richard Hobbs. Originally published in JMIR Public Health and Surveillance (<http://publichealth.jmir.org>), 17.11.2020. This is an open-access article distributed under the terms of the Creative Commons Attribution License (<https://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in JMIR Public Health and Surveillance, is properly cited. The complete bibliographic information, a link to the original publication on <http://publichealth.jmir.org>, as well as this copyright and license information must be included.

Viewpoint

Leveraging a Cloud-Based Critical Care Registry for COVID-19 Pandemic Surveillance and Research in Low- and Middle-Income Countries

CRIT Care Asia^{1,2*}; Madiha Hashmi^{3*}, MD; Abi Beane^{1*}, MSc, PhD; Srinivas Murthy⁴, MD, MHSc; Arjen M Dondorp¹, MD, PhD; Rashan Haniffa⁵, MD, DPhil

¹Collaboration for Research, Improvement and Training in Critical Care in Asia, Mahidol Oxford Tropical Medicine Research Unit, Faculty of Tropical Medicine, Mahidol University, Bangkok, Thailand

²Please see acknowledgements section for list of collaborators, Bangkok, Thailand

³Department of Critical Care, Ziauddin University, Karachi, Pakistan

⁴Department of Pediatrics, University of British Columbia, Vancouver, BC, Canada

⁵Collaboration for Research, Improvement and Training in Critical Care in Asia, Mahidol Oxford Tropical Medicine Research Unit, Bangkok, Thailand

*these authors contributed equally

Corresponding Author:

Abi Beane, MSc, PhD

Collaboration for Research, Improvement and Training in Critical Care in Asia

Mahidol Oxford Tropical Medicine Research Unit

Faculty of Tropical Medicine, Mahidol University

Bangkok

Thailand

Phone: 66 07841131252

Email: abi@nicsslk.com

Abstract

The COVID-19 pandemic has revealed limitations in real-time surveillance needed for responsive health care action in low- and middle-income countries (LMICs). The Pakistan Registry for Intensive Care (PRICE) was adapted to enable International Severe Acute Respiratory and emerging Infections Consortium (ISARIC)-compliant real-time reporting of severe acute respiratory infection (SARI). The cloud-based common data model and standardized nomenclature of the registry platform ensure interoperability of data and reporting between regional and global stakeholders. Inbuilt analytics enable stakeholders to visualize individual and aggregate epidemiological, clinical, and operational data in real time. The PRICE system operates in 5 of 7 administrative regions of Pakistan. The same platform supports acute and critical care registries in eleven countries in South Asia and sub-Saharan Africa. ISARIC-compliant SARI reporting was successfully implemented by leveraging the existing PRICE infrastructure in all 49 member intensive care units (ICUs), enabling clinicians, operational leads, and established stakeholders with responsibilities for coordinating the pandemic response to access real-time information on suspected and confirmed COVID-19 cases (N=592 as of May 2020) via secure registry portals. ICU occupancy rates, use of ICU resources, mechanical ventilation, renal replacement therapy, and ICU outcomes were reported through registry dashboards. This information has facilitated coordination of critical care resources, health care worker training, and discussions on treatment strategies. The PRICE network is now being recruited to international multicenter clinical trials regarding COVID-19 management, leveraging the registry platform. Systematic and standardized reporting of SARI is feasible in LMICs. Existing registry platforms can be adapted for pandemic research, surveillance, and resource planning.

(*JMIR Public Health Surveill* 2020;6(4):e21939) doi:[10.2196/21939](https://doi.org/10.2196/21939)

KEYWORDS

critical care; registry; informatics; COVID-19; severe acute respiratory infection; pandemic; surveillance; cloud-based; research; low-and-middle-income countries

Introduction

The COVID-19 pandemic has revealed limitations in capacity for real-time surveillance needed for responsive health care action in low- and middle-income countries (LMICs), where infrastructure and institutional partnerships to facilitate accurate and timely reporting of clinical and operational data are often absent [1,2]. This absence of data impedes the ability of researchers, clinicians, and health policy leaders to identify context-specific risk factors associated with severe disease or death and make informed decisions regarding public health policy, critical care admission, and management of patients with severe acute respiratory infection (SARI) [3,4].

Critical care services are a key component of pandemic preparedness in health systems [5]. In LMICs, critical care services are already limited outside the pandemic context, and technical and human resources are often already overburdened with existing endemic illness [6]. Limitations in resources, diagnostics, and training are potential barriers to the operationalization of internationally comparable surveillance and translational research in many LMICs. The paucity of LMIC representation in international datasets and in research risks disenfranchising large parts of the world [7].

The effectiveness of a response to a pandemic threat depends critically on the speed and focus of that response. At the core of the World Health Organization (WHO) plan is the Clinical Characterization Protocol (CCP) developed by the International Severe Acute Respiratory and emerging Infections Consortium (ISARIC) [8]. ISARIC aims to facilitate real-time research on diseases caused by novel pathogens of public health concern to save lives and inform public health policy early in and during outbreaks [8]. The open-access protocols use standardized and refined case report forms, information documents, and consent documents, and they offer a tiered (0-3) biological sampling schedule. The WHO Ethics Review Committee approved a global master protocol for the ISARIC CCP and endorsed its use in outbreaks of public health interest [9].

Pakistan Registry of Intensive CarE (PRICE) was established in 2018 with the support of Wellcome. PRICE supports a national network of 49 sites in Pakistan recording over 2000 monthly critical care admissions [10]. PRICE provides real-time reporting on the epidemiology, severity of illness, treatment, microbiology, and outcomes of intensive care unit (ICU) patients alongside information regarding the workforce, unit activity, unit acuity, and resource utilization in the ICU. Work already undertaken by PRICE has identified wide regional disparity in the availability of critical care resources [11]. Similarly, characterization of the current pandemic in relation to available resources is an essential tool in the management of an outbreak [6]. The PRICE platform, codesigned with clinicians, leverages the NICS-MORU platform, a cloud-based system that allows

real-time monitoring of case mix, performance metrics, and benchmarking for acute and critical care; it is currently deployed in over 11 LMICs and 180 acute and critical care units in South Asia and sub-Saharan Africa [3]. PRICE and NICS-MORU are founding members of the Wellcome-MORU Collaboration for Research, Improvement and Training in Critical Care Asia (CRIT Care Asia), established in August 2019, which will support adaptation and implementation of the PRICE reporting model in nine countries in South and Southeast Asia: Bangladesh, India, Laos, Nepal, Malaysia, Pakistan, Sri Lanka, Thailand, and Vietnam.

This viewpoint describes the adaptation and operationalization of the PRICE platform to conform with all tiers of the ISARIC CCP for SARI in participating ICUs. It also outlines the development of a rapidly deployable standalone SARI application for use in ICUs and acute care facilities in Pakistan and beyond.

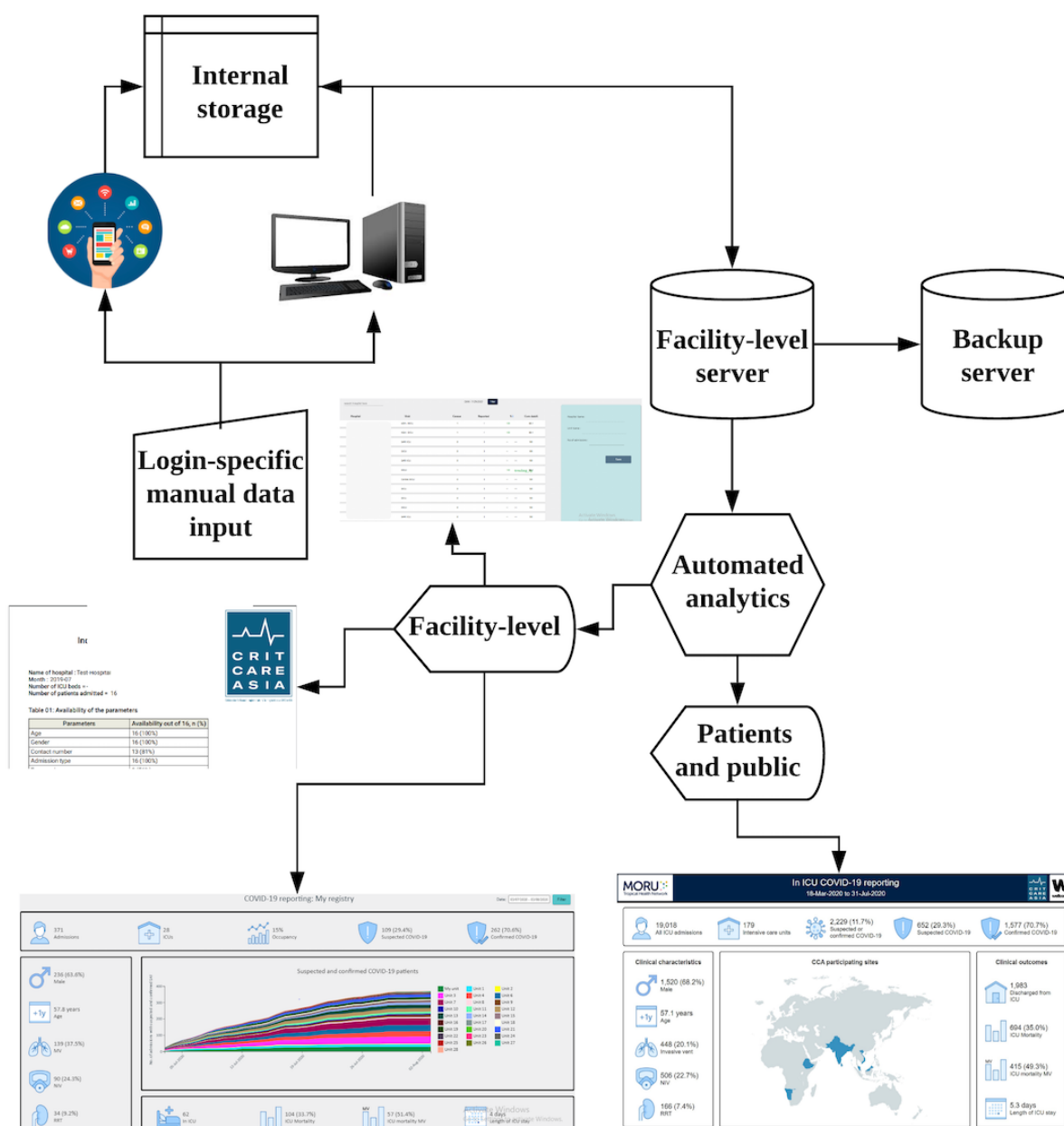
Approach

The ISARIC tier 0-3 CCP was incorporated into the PRICE platform in March 2020. COVID-19 diagnosis was mapped to existing Acute Physiology and Chronic Health Evaluation (APACHE) IV diagnostic codes [12]. Variables were added using a standardized nomenclature, Systematized Nomenclature of Medicine Clinical Terms (SNOMED CT), that was already operationalized in the platform, enhancing interoperability at the organizational level and facilitating sharing with ISARIC [13].

Leveraging the existing PRICE data collection methods and the ISARIC CCP protocol, training was provided to existing data collectors and clinical leads in the additional data set and in dashboard navigation. The process of data entry, storage, and visualization is illustrated in Figure 1. Training was facilitated by the Wellcome-funded NICS-MORU registry development and support team based in Sri Lanka. The NICS-MORU team facilitates registry implementation and adoption across sites in South Asia and sub-Saharan Africa. The team provided remote training via web-based videoconferencing and instant messaging apps, overcoming challenges such as restricted travel. These processes, along with other implementation and data monitoring tools, have been explained in detail in previous publications [3].

In addition, 24-hour support via messaging provided operational, data entry, and technical assistance. Inbuilt platform features (completeness, validation, consistency) and raw data capture ensure the quality of the data for surveillance and subsequent research [14]. Platform-enabled reports and dashboards visualize real-time operational, clinical, and outcome data of suspected and confirmed COVID-19 cases in the ICUs. Metrics including case mix, service utilization, and unit performance are made accessible to the relevant stakeholders.

Figure 1. Scheme outlining the process of data entry, storage, and visualization in the Pakistan Registry for Intensive CarE (PRICE) platform.



A web-based report and dashboard were integrated within the existing PRICE platform to visualize real-time operational, clinical, and outcome data of suspected and confirmed COVID-19 cases in the ICUs. Metrics included use of respiratory support, renal replacement therapy and outcomes, and the availability of ICU beds and ventilators. Dashboards were made accessible to the relevant stakeholders through their existing logins via tablet or desktop. Printable weekly reports provide more detailed analyses of the case mix, severity of illness, microbiology, and outcomes.

The ISARIC CCP-compliant SARI reporting tool was then developed as a standalone mobile and desktop application for use in health care facilities that are not currently part of an existing registry network. Mirroring the PRICE platform, the application requires minimal data connectivity (3G) and has

offline functionality. This standalone application provides a mechanism for capturing SARI case reports in a systematic and internationally comparable manner, providing rapid onboarding of health care organizations with minimal information technology infrastructure while enabling institutions to retain ownership of data and use for local service evaluation.

Relevant Changes

ISARIC-compliant SARI reporting was successfully developed and implemented in 49 ICUs within the PRICE network over a four-week period. Data completeness for ISARIC tiers 0 and 1 was above 97%, overcoming perennial LMIC data quality challenges and ensuring that the data are suitable for high-quality research [14]. As of May 24, 2020, clinicians and health service organizers had accessed real-time information on 592 suspected

and confirmed COVID-19 cases via secure portals within their ICUs. Real-time aggregate data on ICU occupancy, acuity, resource utilization, and remaining capacity is being used by ICU operational leads to better inform organizations of interdepartmental resources and coordination of regional public health strategies in partnership with members of the government's pandemic task force. Information regarding treatment utilization (eg, ventilation, noninvasive ventilation, renal replacement therapy, vasopressors) is being used by the Faculty of Critical Care Medicine of the College of Physicians and Surgeons Pakistan to guide regional training priorities for health care workers who are being upskilled in the management and care of critically ill patients with acute respiratory illness. The same information has guided biweekly interprofessional web-based meetings with PRICE and CRIT Care Asia members discussing context-specific treatment strategies, and it has informed priorities for the management of patients with COVID-19 in LMICs [5]. PRICE-collaborating ICUs are now being recruited to registry-embedded international multicenter research clinical trials—site recruitment to the Randomized, Embedded, Multifactorial Adaptive Platform Trial for Community-Acquired Pneumonia (REMAP-CAP) COVID-19 trial is underway in three countries in the CRIT Care Asia network—with registry-enabled clinical and epidemiological data informing the selection of context-specific interventions and site enrollment. The ISARIC CCP-compliant data set and inbuilt registry audit and feedback mechanisms have since been made available to 180 ICUs within the CRIT Care Asia network. The standalone SARI reporting application is open access for future collaborators through ISARIC [8]. SARI reporting for CRIT Care Asia is also publicly available [15].

A key challenge facing CRIT Care Asia and similar international consortiums operationalizing pandemic surveillance reporting are the administrative and technical barriers to data curation and sharing. CRIT Care Asia's federated approach to data storage, which enables sites to retain ownership of data while contributing metadata to national and international networks with minimal site-level data transformation, has helped overcome these barriers.

Conclusion

The COVID-19 pandemic represents a major challenge to health care services worldwide, particularly for ICUs. In LMICs, the surge of SARI patients is placing unprecedented stress on existing services, infrastructure, and health care workers. For health care systems worldwide, the challenge of operationalizing disease-specific data capture during a pandemic may best be met by harnessing existing digital health solutions, such as registries, which in a nonpandemic context enable multicenter monitoring and reporting of critical care case mix, workload, and availability of ICU resources. To realize the potential of registries, however, investment is needed in robust health care technology that is capable of rapid transformation, scalability, and interoperability [2]. Those responsible for commissioning and developing registries should be mindful of the potential uses of such systems as part of a wider public health strategy and of the need to build systems with the capabilities described above. Realizing this capability in LMICs would be a significant step forward in achieving an effective and coordinated global pandemic response.

Acknowledgments

CRIT Care Asia would like to thank all Pakistan Registry of Intensive Care collaborators and the registry team that engaged in this work during these challenging times. This work was undertaken as part of the existing Wellcome Innovations Flagship award of CRIT Care Asia. The CRIT Care Asia group includes the following collaborators: Site collaborators: Ahmed Farooq, Arshad Taqi, Ashok Kumar, Attaur Rehman, Iqbal Hussain, Irfan Malik, Jodat Saleem, Mobin Chaudhry, Mohammad Hayat, Muhammad Asim Rana, Muhammad Nasir Khoso, Muhammad Sheharyar, Naseem Ali Shaikh, Nawal Salahuddin, Rana Imran Sikander, Rashid Naseem Khan, Safdar Rehman, Syed Muneeb Ali, Sairah Babar, and Quratul Ain Khan. Registry Team: Udara Attanyake, Sri Darshana, Pramodya Ishani, Issrah Jawad, Chamira Kodippily, Dilanthi Priyadarshani, Thalha Rashan, Mohiuddin Shiekh, Timo Tolppa, and Ishara Udayanga. Writing Group: Madiha Hashmi, Abigail Beane, Srinivas Murthy, Arjen M Dondorp, and Rashan Haniffa.

Authors' Contributions

MH, AB, and RH conceived and designed the paper. All collaborators collected data. AB and MH drafted the manuscript. RH, AMD, and SM critically revised the manuscript. All collaborators provided final approval of the article. AB, RH, and AMD obtained funding. AB takes overall responsibility for the work.

Conflicts of Interest

None declared.

References

1. Buckee C. Improving epidemic surveillance and response: big data is dead, long live big data. *Lancet Digit Health* 2020 May;2(5):e218-e220 [[FREE Full text](#)] [doi: [10.1016/S2589-7500\(20\)30059-5](https://doi.org/10.1016/S2589-7500(20)30059-5)] [Medline: [32518898](https://pubmed.ncbi.nlm.nih.gov/32518898/)]

2. Mahmood S, Hasan K, Colder Carras M, Labrique A. Global Preparedness Against COVID-19: We Must Leverage the Power of Digital Health. *JMIR Public Health Surveill* 2020 Apr 16;6(2):e18980 [FREE Full text] [doi: [10.2196/18980](https://doi.org/10.2196/18980)] [Medline: [32297868](https://pubmed.ncbi.nlm.nih.gov/32297868/)]
3. Beane A, De Silva AP, Athapattu PL, Jayasinghe S, Abayadeera AU, Wijerathne M, et al. Addressing the information deficit in global health: lessons from a digital acute care platform in Sri Lanka. *BMJ Glob Health* 2019;4(1):e001134 [FREE Full text] [doi: [10.1136/bmjgh-2018-001134](https://doi.org/10.1136/bmjgh-2018-001134)] [Medline: [30775004](https://pubmed.ncbi.nlm.nih.gov/30775004/)]
4. Salluh J, Ramos FDS. A COVID-19 Dashboard: Data Analytics to Aid Resource Allocation in Intensive Care Units. *ICU Management and Practice* 2020;20(1):36-37 [FREE Full text]
5. Dondorp AM, Hayat M, Aryal D, Beane A, Schultz MJ. Respiratory Support in COVID-19 Patients, with a Focus on Resource-Limited Settings. *Am J Trop Med Hyg* 2020 Jun;102(6):1191-1197 [FREE Full text] [doi: [10.4269/ajtmh.20-0283](https://doi.org/10.4269/ajtmh.20-0283)] [Medline: [32319424](https://pubmed.ncbi.nlm.nih.gov/32319424/)]
6. Harris C, Carson G, Baillie JK, Horby P, Nair H. An evidence-based framework for priority clinical research questions for COVID-19. *J Glob Health* 2020 Jun;10(1):011001 [FREE Full text] [doi: [10.7189/jogh.10.011001](https://doi.org/10.7189/jogh.10.011001)] [Medline: [32257173](https://pubmed.ncbi.nlm.nih.gov/32257173/)]
7. Rudd KE, Johnson SC, Agesa KM, Shackelford KA, Tsoi D, Kievlan DR, et al. Global, regional, and national sepsis incidence and mortality, 1990-2017: analysis for the Global Burden of Disease Study. *Lancet* 2020 Jan 18;395(10219):200-211 [FREE Full text] [doi: [10.1016/S0140-6736\(19\)32989-7](https://doi.org/10.1016/S0140-6736(19)32989-7)] [Medline: [31954465](https://pubmed.ncbi.nlm.nih.gov/31954465/)]
8. Simpson CR, Beever D, Challen K, De Angelis D, Fragaszy E, Goodacre S, NIHR hibernated influenza studies collaborative group. The UK's pandemic influenza research portfolio: a model for future research on emerging infections. *Lancet Infect Dis* 2019 Aug;19(8):e295-e300. [doi: [10.1016/S1473-3099\(18\)30786-2](https://doi.org/10.1016/S1473-3099(18)30786-2)] [Medline: [31006605](https://pubmed.ncbi.nlm.nih.gov/31006605/)]
9. Docherty AB, Harrison EM, Green CA, Hardwick HE, Pius R, Norman L, ISARIC4C investigators. Features of 20 133 UK patients in hospital with covid-19 using the ISARIC WHO Clinical Characterisation Protocol: prospective observational cohort study. *BMJ* 2020 May 22;369:m1985 [FREE Full text] [doi: [10.1136/bmj.m1985](https://doi.org/10.1136/bmj.m1985)] [Medline: [32444460](https://pubmed.ncbi.nlm.nih.gov/32444460/)]
10. Hashmi M, Beane A, Taqi A, Memon MI, Athapattu P, Khan Z, et al. Pakistan Registry of Intensive CarE (PRICE): Expanding a lower middle-income, clinician-designed critical care registry in South Asia. *J Intensive Care Soc* 2019 Aug;20(3):190-195 [FREE Full text] [doi: [10.1177/1751143718814126](https://doi.org/10.1177/1751143718814126)] [Medline: [31447910](https://pubmed.ncbi.nlm.nih.gov/31447910/)]
11. Hashmi M, Taqi A, Memon MI, Ali SM, Khaskheli S, Sheharyar M, et al. A national survey of critical care services in hospitals accredited for training in a lower-middle income country: Pakistan. *J Crit Care* 2020 Aug 21;60:273-278 [FREE Full text] [doi: [10.1016/j.jcrc.2020.08.017](https://doi.org/10.1016/j.jcrc.2020.08.017)] [Medline: [32942162](https://pubmed.ncbi.nlm.nih.gov/32942162/)]
12. Zimmerman JE, Kramer AA, McNair DS, Malila FM. Acute Physiology and Chronic Health Evaluation (APACHE) IV: hospital mortality assessment for today's critically ill patients. *Crit Care Med* 2006 May;34(5):1297-1310. [doi: [10.1097/01.CCM.0000215112.84523.F0](https://doi.org/10.1097/01.CCM.0000215112.84523.F0)] [Medline: [16540951](https://pubmed.ncbi.nlm.nih.gov/16540951/)]
13. Elkin PL, Brown SH, Husser CS, Bauer BA, Wahner-Roedler D, Rosenbloom ST, et al. Evaluation of the content coverage of SNOMED CT: ability of SNOMED clinical terms to represent clinical problem lists. *Mayo Clin Proc* 2006 Jun;81(6):741-748. [doi: [10.4065/81.6.741](https://doi.org/10.4065/81.6.741)] [Medline: [16770974](https://pubmed.ncbi.nlm.nih.gov/16770974/)]
14. Black N, Payne M. Directory of clinical databases: improving and promoting their use. *Qual Saf Health Care* 2003 Oct;12(5):348-352 [FREE Full text] [doi: [10.1136/qhc.12.5.348](https://doi.org/10.1136/qhc.12.5.348)] [Medline: [14532366](https://pubmed.ncbi.nlm.nih.gov/14532366/)]
15. Critical illness. MORU Tropical Health Network. URL: <https://www.tropmedres.ac/units/moru-bangkok/malaria/studies-study-sites/critical-illness> [accessed 2020-11-12]

Abbreviations

APACHE: Acute Physiology and Chronic Health Evaluation

CCP: Clinical Characterization Protocol

CRIT Care Asia: Collaboration for Research, Improvement and Training in Critical Care Asia

ICU: intensive care unit

ISARIC: International Severe Acute Respiratory and emerging Infections Consortium

LMICs: low- and middle-income countries

PRICE: Pakistan Registry for Intensive CarE

REMAP-CAP: Randomized, Embedded, Multifactorial Adaptive Platform Trial for Community-Acquired Pneumonia

SARI: severe acute respiratory infection

SNOMED CT: Systematized Nomenclature of Medicine Clinical Terms

WHO: World Health Organization

Edited by G Eysenbach; submitted 29.06.20; peer-reviewed by T Goto, T Clavier, M Apolaya Segura; comments to author 28.07.20; revised version received 04.08.20; accepted 20.10.20; published 23.11.20.

Please cite as:

CRIT Care Asia, Hashmi M, Beane A, Murthy S, Dondorp AM, Haniffa R

Leveraging a Cloud-Based Critical Care Registry for COVID-19 Pandemic Surveillance and Research in Low- and Middle-Income Countries

JMIR Public Health Surveill 2020;6(4):e21939

URL: <http://publichealth.jmir.org/2020/4/e21939/>

doi: [10.2196/21939](https://doi.org/10.2196/21939)

PMID: [33147162](https://pubmed.ncbi.nlm.nih.gov/33147162/)

© CRIT Care Asia, Madiha Hashmi, Abi Beane, Srinivas Murthy, Arjen M Dondorp, Rashan Haniffa. Originally published in JMIR Public Health and Surveillance (<http://publichealth.jmir.org>), 23.11.2020. This is an open-access article distributed under the terms of the Creative Commons Attribution License (<https://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in JMIR Public Health and Surveillance, is properly cited. The complete bibliographic information, a link to the original publication on <http://publichealth.jmir.org>, as well as this copyright and license information must be included.

Original Paper

The Relationship Between Demographic, Socioeconomic, and Health-Related Parameters and the Impact of COVID-19 on 24 Regions in India: Exploratory Cross-Sectional Study

Ravi Philip Rajkumar¹, MD

Jawaharlal Institute of Postgraduate Medical Education and Research, Pondicherry, India

Corresponding Author:

Ravi Philip Rajkumar, MD

Jawaharlal Institute of Postgraduate Medical Education and Research

Dhanvantari Nagar Post

Pondicherry, 605006

India

Phone: 91 4132296280

Email: ravi.psych@gmail.com

Abstract

Background: The impact of the COVID-19 pandemic has varied widely across nations and even in different regions of the same nation. Some of this variability may be due to the interplay of pre-existing demographic, socioeconomic, and health-related factors in a given population.

Objective: The aim of this study was to examine the statistical associations between the statewide prevalence, mortality rate, and case fatality rate of COVID-19 in 24 regions in India (23 states and Delhi), as well as key demographic, socioeconomic, and health-related indices.

Methods: Data on disease prevalence, crude mortality, and case fatality were obtained from statistics provided by the Government of India for 24 regions, as of June 30, 2020. The relationship between these parameters and the demographic, socioeconomic, and health-related indices of the regions under study was examined using both bivariate and multivariate analyses.

Results: COVID-19 prevalence was negatively associated with male-to-female sex ratio (defined as the number of females per 1000 male population) and positively associated with the presence of an international airport in a particular state. The crude mortality rate for COVID-19 was negatively associated with sex ratio and the statewide burden of diarrheal disease, and positively associated with the statewide burden of ischemic heart disease. Multivariate analyses demonstrated that the COVID-19 crude mortality rate was significantly and negatively associated with sex ratio.

Conclusions: These results suggest that the transmission and impact of COVID-19 in a given population may be influenced by a number of variables, with demographic factors showing the most consistent association.

(*JMIR Public Health Surveill* 2020;6(4):e23083) doi:[10.2196/23083](https://doi.org/10.2196/23083)

KEYWORDS

burden of disease; COVID-19; diarrheal disease; ischemic heart disease; population size; sex ratio

Introduction

The COVID-19 pandemic, caused by the novel coronavirus SARS-CoV-2, has emerged as perhaps the most significant health crisis of our time [1]. An unexpected observation in the context of this pandemic has been the wide variations in prevalence, mortality rate, and case fatality rate across affected countries, which cannot be wholly explained on the basis of differences in the virulence of SARS-CoV-2 strains [2-5]. While some of this variation may reflect differences in health care and testing capacity across nations, it remains important to examine

the role of other factors in causing this variability, particularly socioeconomic determinants of health [6,7]. There is already evidence that social factors, such as perceived sociability, socioeconomic disadvantage, health literacy, trust in regulatory authorities, and the speed and stringency of measures instituted to control the spread of COVID-19, can crucially influence these variables [1,2,7]. These social factors interact with individual psychological responses to influence behavior either positively or negatively—for example, an adaptive (“functional”) level of fear of COVID-19 was associated with better adherence to public health safety measures in an international sample of

adults, while self-reported depression had the opposite effect [8]. Preliminary research has found that demographic and socioeconomic factors can influence variability in the spread and impact of COVID-19 not only between countries but within a given country; in an ecological analysis of data from the United States, poverty, number of elderly people, and population density were positively correlated with COVID-19 incidence and mortality rates [9].

At the time of writing this paper, India ranked third among all nations in terms of the total number of confirmed cases of COVID-19, following the United States and Brazil, with over 3,000,000 cases reported as of August 25, 2020 [10]. Following the initial identification of 563 positive cases, the Indian government instituted a nation-wide lockdown for a period of 21 days, which began at midnight on March 24, 2020, and was gradually relaxed over the next 2 months [11]. Data from the initial phase of the lockdown suggested that this measure significantly reduced the transmission of COVID-19; however, this number rapidly increased in subsequent months. This rapid increase was not uniform: across the 32 states and territories of India, certain states have reported over 1000 cases, while others have reported far lower numbers despite their geographical proximity to these states [12,13].

Besides the demographic and socioeconomic variables discussed above, an important factor that may influence such variations in the Indian context is the availability and quality of health care. Health care facilities in India are unevenly distributed, with a significant urban-rural divide, and this inequality has been further exacerbated by the COVID-19 pandemic [14,15].

Keeping the above in mind, an exploratory study was conducted to examine the relationship between demographic, socioeconomic, and health-related indices and measures of the spread and impact of COVID-19 across different states in India. These indices were drawn both from published research to date and from factors hypothesized to influence the spread and outcome of COVID-19.

Methods

COVID-19-Related Data

The current study was an exploratory cross-sectional study based on data officially released by the Government of India. Information related to COVID-19 was obtained from the website of the Ministry of Health and Family Welfare, which provides information on the total number of cases, active cases, recovered cases, and deaths for each state and territory of India and is updated every 24 hours [16]. Data for this study were recorded from the above source on June 30, 2020. Out of the 32 states and territories, only the 24 regions that reported at least 500 cases and one or more deaths were selected, to permit a meaningful computation of COVID-19-related indices.

After obtaining information on the population of each region from the Government of India's official census data [17], and verifying it against updated projections for 2020 from the Unique Identification Authority of India [18], the following indices related to COVID-19 were calculated for each state:

- The estimated prevalence rate: the total number of cases (active, recovered, and deceased) per 1 million population
- The crude mortality rate: the total number of reported deaths due to COVID-19 per 1 million population
- The case fatality rate: the ratio of deaths to all cases with outcomes (death or recovery), expressed as a percentage.

Demographic Information

Details on population per state were recorded using the census data cited above, as well as the updated population projections for the year 2020 provided by the Unique Identification Authority of India, while information on population density was obtained from the National Institution for Transforming India (NITI-Aayog), the Government of India's official source of data on demographic and socioeconomic variables [17-19]. As age and male sex have both been associated with mortality due to COVID-19, mean life expectancy for each state and male-to-female sex ratio per state, defined as the number of females per 1000 male population, were obtained from the same source [9,20].

Socioeconomic Variables

Information on literacy rates and female literacy rates per state was obtained from official census data, while information on poverty, defined as the percentage of people living below the poverty line in each state, was obtained from the data published by the Ministry of Social Justice and Empowerment [21]. Information on indices related to law and order—statewise rates of homicide, accident, and rape—were obtained from the official statistics published in 2018 by the National Crime Records Bureau [22]. This information was included due to the proposed role of law enforcement, and adherence to it, in containing the spread of COVID-19 [2]. As international air travel has also been linked to the spread of COVID-19, information on which states had a functional international airport was obtained from the website of the Airports Authority of India [23,24].

Health-Related Variables

Information on a number of general indices of health for each state—the maternal, infant, and under-five mortality rates and the percentage of children under 24 months who were fully immunized—was obtained from official NITI-Aayog data, which was updated for the 2015-2016 fiscal year. In addition, information on the percentage of disability-adjusted life years (DALYs) for 6 common health conditions—diarrheal disease, lower respiratory infection, tuberculosis, diabetes mellitus, chronic obstructive pulmonary disease, and ischemic heart disease—was obtained from the official report on state-level disease burden commissioned by the Department of Health Research, Ministry of Health and Family Welfare, and published in 2017 [25]. These variables were studied due to the emerging evidence on the role of medical comorbidities in determining the outcome of COVID-19, as well as the hypothesized role of past infectious diseases in influencing the host immune response to SARS-CoV-2 [3,26]. In view of the proposed relationship between depression and decreased adherence to public health measures, estimated statewise prevalence rates of depression were obtained from the 2017 Global Burden of Disease Study

[27]. A complete list of the data sources used in this study is provided in [Table 1](#).

Table 1. Official data sources used for the analyses in this study.

Study variable	Data source
Total population per state	Census of India [17]; Unique Identification Authority of India projections [18]
Population density per state; mortality indices per state	National Institution for Transforming India (NITI Aayog) [19]
Literacy rates per state	Census of India [17]
Percentage living below the poverty line per state	Ministry of Social Justice and Empowerment [21]
Crime-related statistics per state	National Crime Records Bureau Report, 2018 [22]
Presence of international airports in a given state	Airports Authority of India [24]
Disease burden per state	India: Health of the Nation's States – the India State-Level Disease Burden Initiative [25]
Estimated prevalence of depression per state	Global Burden of Disease Study, Indian data [27]
COVID-19 statistics	Ministry of Health and Family Welfare [16]

Ethical Issues

This study was based on an analysis of data available in the public domain and did not involve any human subjects. As per the Institute Ethics Committee guidelines of the author's institution, such analyses do not require formal approval by the committee.

Data Analysis

Data were analyzed using SPSS, version 20.0 (IBM Corp). Prior to bivariate analysis, all study parameters were tested for normality. As the COVID-19 indices—prevalence, mortality rate, and case fatality rate—were not normally distributed ($P < .01$ for all indices, Shapiro-Wilk test), the Spearman rank correlation coefficient (ρ) was used to test the hypothesis of a monotonic relationship between these indices and the aforementioned demographic, socioeconomic, and health-related indices. For the purpose of this study, a significance level of $P < .05$ was considered significant. This value carries with it a certain risk of maximizing the significance of marginal or potentially false-positive findings; however, given the exploratory nature of this study, it was adopted in order to avoid rejecting potentially significant associations on the basis of a more or less arbitrary cut-off value [28,29].

To confirm the strength of these associations, a multivariate linear regression was carried out for each of the individual COVID-19 indices. Only those variables that were associated with these indices at a significance of $P < .05$ or below in univariate or multivariate analyses were included in the multivariate analyses for each index.

Data Availability Statement

All data used in this study were obtained from public-domain data sources ([Table 1](#)). A complete data set is available in [Multimedia Appendix 1](#).

Results

Sample Description

Data were obtained for 23 Indian states and one territory (Delhi) for the period up to June 30, 2020. As of this date, 566,840 confirmed cases of COVID-19, and 17,337 deaths due to the disease, had been officially reported. The mean and standard deviation values of prevalence, crude mortality rate, and case fatality rate for the entire sample were 504.13 (SD 896.64) cases per 1 million population, 12.68 (SD 30.03) deaths per 1 million population, and 2.77 (SD 2.21) deaths per 100 cases, respectively. There was a wide range of variation across the COVID-19 indices, with prevalence ranging from 61.25 (Jharkand) to 4440.03 (Delhi) per 1 million population, mortality ranging from 0.24 (Tripura) to 140.19 (Delhi) per 1 million population, and case fatality rate ranging from 0.09% (Tripura) to 7.9% (Maharashtra) (see [Multimedia Appendix 2](#) for the complete details.)

Correlations between the demographic, socioeconomic, and health-related indices listed above and the COVID-19 indices are provided in [Table 2](#). The raw data underlying all these analyses are available in [Multimedia Appendix 1](#).

Table 2. Relationship (Spearman rank correlation coefficient [ρ]) between demographic, socioeconomic, health-related, and COVID-19 indices in 24 Indian regions for the period ending June 30, 2020. Values significant at $P < .05$ are indicated in italics.

Variable	COVID-19 estimated prevalence		COVID-19 crude mortality rate		COVID-19 case fatality ratio	
	ρ	<i>P</i> value	ρ	<i>P</i> value	ρ	<i>P</i> value
Demographic indices						
Total population	-0.240	.26	0.225	.29	<i>0.526*</i>	<i>.009*</i>
Population density	-0.129	.57	-0.051	.82	0.092	.68
Sex ratio	<i>-0.571*</i>	<i>.008*</i>	<i>-0.517*</i>	<i>.02*</i>	-0.369	.10
Indices of human development						
Life expectancy	<i>0.469*</i>	<i>.03*</i>	<i>0.489*</i>	<i>.02*</i>	0.230	.32
Percentage living below the poverty line	<i>-0.466*</i>	<i>.04*</i>	-0.418	.06	-0.251	.27
Literacy rate	<i>0.453*</i>	<i>.03*</i>	0.155	.48	-0.030	.89
Indices of law and order						
Homicide rate	-0.171	.43	-0.313	.14	-0.364	.08
Rape rate	-0.044	.84	-0.052	.81	-0.149	.49
Accidental death rate	-0.350	.10	-0.309	.15	-0.149	.50
Health indicators						
Maternal mortality rate	0.353	.15	<i>-0.499*</i>	<i>.04*</i>	-0.330	.18
Infant mortality rate	<i>-0.474*</i>	<i>.02*</i>	-0.276	.19	-0.090	.68
Under-five mortality rate	-0.406	.08	<i>-0.476*</i>	<i>.04*</i>	-0.304	.21
Disability-adjusted life years						
Diarrheal disease	<i>-0.563*</i>	<i>.004*</i>	<i>-0.500*</i>	<i>.01*</i>	-0.259	.22
Tuberculosis	-0.224	.29	0.024	.91	0.121	.57
Chronic obstructive pulmonary disease	0.225	.29	0.262	.22	0.295	.16
Lower respiratory tract infection	-0.338	.12	-0.256	.23	-0.135	.53
Diabetes mellitus	0.348	.16	0.244	.33	0.173	.49
Ischemic heart disease	<i>0.476*</i>	<i>.02*</i>	<i>0.535*</i>	<i>.007*</i>	0.367	.08
Iron deficiency anemia	-0.116	.60	0.030	.89	0.125	.57
Depression, estimated prevalence	0.373	.09	0.176	.43	0.006	.98
Suicide rate	0.261	.22	0.090	.67	0.020	.93

* P values $< .05$

Relationship Between Demographic Variables and COVID-19 Indices

COVID-19 prevalence for each region was significantly and negatively correlated with sex ratio ($P = .008$) and was positively associated with life expectancy ($P = .03$) (Table 2). Crude mortality rate was positively correlated with life expectancy and negatively correlated with sex ratio (both $P < .05$). In contrast, the case fatality rate was significantly correlated with the total population of each region ($P < .009$).

Relationship Between Socioeconomic Variables And COVID-19 Indices

The prevalence of COVID-19 showed a positive association with the life expectancy and literacy rate, and a negative

trend-level association with the percentage of people living below the poverty line (all $P_s < .05$) (Table 2). No significant correlations were observed between COVID-19 mortality and case fatality rates and any socioeconomic parameter, though a negative association of marginal significance was observed between the percentage of individuals living below the poverty line and the crude mortality rate ($P = .06$). As the presence or absence of an international airport was a dichotomous variable and the COVID-19 indices were not normally distributed, the Mann-Whitney U test was used to compare these indices. States with an international airport had a significantly higher estimated COVID-19 prevalence ($U = 118.0$, $P = .007$) but did not differ significantly in terms of mortality or case fatality. None of the putative indices of law and order were significantly associated with any COVID-19 parameters.

Relationship Between Health-Related Variables and COVID-19 Indices

COVID-19 prevalence was significantly and negatively correlated with the burden of diarrheal disease per state ($P=.004$) and the infant mortality rate at $P<.05$, and was positively associated with the burden of ischemic heart disease ($P=.02$) (Table 2). In contrast, the mortality rate showed a significant positive correlation with the burden of ischemic heart disease ($P=.007$), and was negatively associated with the maternal mortality rate, under-five mortality rate, and burden of diarrheal disease (all $P_s<.05$). None of the health-related variables were significantly associated with the case fatality rate. The two indices of mental health—statewise suicide rate and estimated prevalence of depression—were not significantly related to any COVID-19 indices, though a marginal positive association with estimated prevalence was found for depression ($P=.09$).

Multivariate Analyses

All variables that were significantly associated with COVID-19 indices at a significance level of $P<.05$ or lower were selected for multivariate linear regression analyses. For COVID-19 estimated prevalence, these variables were sex ratio, life expectancy, percentage of the population living below the poverty line, literacy rate, infant mortality rate, and DALYs due to diarrheal disease and ischemic heart disease. The final model explained only 8% of the variance in prevalence (adjusted $R^2=0.080$), and analysis of variance yielded an F value of 1.248 ($df=13$), with a significance of $P=.35$, suggesting that the null hypothesis should be retained. None of the individual variables were significantly associated with COVID-19 prevalence in this model.

For the COVID-19 crude mortality rate, the variables entered in the model were sex ratio, life expectancy, maternal mortality rate, under-five mortality rate, and DALYs due to diarrheal disease and ischemic heart disease. The final model explained 20.4% of the variance in crude mortality rate (adjusted $R^2=0.204$) and analysis of variance yielded an F value of 1.682 ($P=.22$), again suggesting that the null hypothesis should be retained. However, among individual variables, sex ratio remained significantly and negatively associated with this variable ($t=-2.361$, $P=.04$).

As only a single study variable—the population size—was associated with the case fatality ratio, multivariate analyses were not carried out in this case.

Discussion

Principal Findings

The results of this preliminary analysis found that certain demographic, socioeconomic, and health-related variables were significantly related to the variability in COVID-19 prevalence, mortality rate, and case fatality rate across 24 regions in India. In particular, COVID-19 prevalence was associated with sex ratio and the burden of diarrheal disease as measured by the percentage of DALYs associated with this disorder, as well as with the presence of an international airport in a given state; COVID-19 mortality was associated with the burden of ischemic

heart disease; and COVID-19 case fatality rate was associated with the total population of each region. The results of the multivariate analyses indicated a negative, significant association between sex ratio and COVID-19 prevalence and mortality.

The association between sex ratio and measures of the impact of COVID-19 is in line with existing research findings. Several clinical case series, both from India and other countries, have reported a preponderance of male patients in hospitalized samples, as well as a link between male sex and mortality due to COVID-19 [30-33]. This phenomenon may be partly explained by sex differences in the immune and inflammatory response to SARS-CoV-2 infection [18]. However, in the Indian context, this relationship could also be influenced by traditionally defined gender roles. These are associated with comparatively greater freedom of movement for men, which places them at a higher risk of exposure to infection [34,35]. The association between the presence of an international airport and the statewise prevalence of COVID-19 is also in line with earlier evidence highlighting the role of international air travel in the transmission of SARS-CoV-2 across nations [23].

Similarly, the link between state-wide differences in the burden of ischemic heart disease and mortality due to COVID-19 is supported by clinical research, which has found an association between the presence of ischemic heart disease and the severity of COVID-19 [36,37]. Moreover, ischemic heart disease is commonly associated with other medical conditions, such as systemic hypertension and chronic renal disease, which themselves worsen the outcome of COVID-19, and COVID-19 has been documented to trigger myocardial injury in patients with pre-existing coronary artery disease [38,39]. No such significant association was found in this study for other medical comorbidities, such as diabetes mellitus or chronic obstructive pulmonary disease. However, such comorbidities have been associated with worse COVID-19 outcomes in clinical samples [37,38]; the failure of this study to confirm this association reflects the limitations inherent in an ecological approach.

Though this could not be confirmed by multivariate analysis, population was positively correlated with the case fatality rate across the different regions of India. This association does not appear to be mediated solely by overcrowding, as no significant association was found between population density and case fatality. A possible explanation for this finding is the unequal distribution and accessibility of health care facilities in India, particularly in areas that have a high total population but a relatively low population density, with limited availability of facilities for testing and treatment in nonurbanized regions [40,41]. Such inequalities may lead to delays in obtaining appropriate treatment [42].

The negative association found between the burden of diarrheal disease and the prevalence of COVID-19 across regions is an unexpected finding, as no such association was found for respiratory diseases such as lower respiratory infection ($\rho=-0.227$, $P=.26$) or pulmonary tuberculosis ($\rho=0.024$, $P=.91$). While it has been postulated that prior exposure to respiratory coronaviruses may moderate the impact of SARS-CoV-2 infection, no such association has been suggested or demonstrated thus far for gastrointestinal infections [3].

However, *in vitro* research has shown that intestinal replication may contribute to the progression of SARS-CoV-2 infection; therefore, it is possible that prior intestinal viral infections, which are a common cause of diarrheal disease, could influence this process [43]. Alternately, this association may be related to behavioral factors, such as reduced population mobility in those with pre-existing gastrointestinal disorders minimizing exposure to SARS-CoV-2, or improved adherence to hand hygiene in those who have experienced prior episodes of diarrheal disease. Finally, this may be a false-positive finding arising from the exploratory nature of the analyses conducted. Though the biological mechanism advanced above has some support in theory, it can neither be confirmed nor disproved using the ecological methods of analysis adopted in this study [44,45].

A number of other associations were observed at a trend level. While the direction of these associations was unexpected in some cases—such as a positive association between COVID-19 prevalence and literacy, and a negative association between COVID-19 and levels of poverty and maternal and under-five mortality rates—these findings must be interpreted with caution, owing to their low statistical significance and the large number of potential confounding factors, as well as the possibility of type I error.

Limitations

The results of this study must be viewed in light of certain limitations. First, demographic, socioeconomic, and health-related data were obtained from official government statistics and populations, which preceded the onset of the COVID-19 outbreak by a period of 3 to 6 years. Therefore, some of this information may not accurately reflect the contemporary situation in the different states of India. Second, this study did not take into account other factors that could influence the spread of COVID-19, such as cultural norms and practices, local variations in climate and temperature, and the efficiency of implementation of quarantine and related measures

[1,2]. Third, the data analysis did not take into account the confounding effects of other variables on the bivariate analyses. Fourth, due to logistic and manpower constraints on testing and case finding, the officially reported statistics on COVID-19 may underestimate the true scope of this problem in India [6,13]. Finally, owing to the cross-sectional nature of this study, it was not possible to assess the relationship between the study variables and trends in the spread of COVID-19, such as the rate of increase in the number of cases.

Conclusions

In conclusion, the results of this study, though limited by the nature of the exploratory analyses and the study design itself, suggest that some of the factors that have been found to influence the outcome of COVID-19 at a clinical level, such as male sex and comorbid ischemic heart disease, also have an impact at the population level. Other unexpected findings, such as the link between population and case fatality and between diarrheal disease burden and COVID-19 prevalence, may represent potential behavioral, socioeconomic, or biological mechanisms that require further elucidation. Though these results may be considered preliminary, they may aid future researchers in studying some of the specific associations found in this study in more depth, and in understanding the advantages and limitations of the approach adopted in this paper. Moreover, despite their limitations, they illustrate the value of ecological analyses in understanding the COVID-19 pandemic, particularly in situations where direct clinical or epidemiological research is not feasible due to safety measures. Ecological analyses can be carried out relatively rapidly and safely in this setting, and the tentative associations observed using this method can be subject to more rigorous analyses in field settings to confirm or refute their validity. Further longitudinal research with more sophisticated statistical modeling and up-to-date data may clarify the role of these and other demographic, socioeconomic, and health-related variables in moderating the impact of COVID-19 within nations, and may inform future strategies to curtail the impact of this pandemic.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Data set comprising all data used in this study.

[[XLS File \(Microsoft Excel File\), 33 KB - publichealth_v6i4e23083_app1.xls](#)]

Multimedia Appendix 2

Variation in COVID-19 indices across 24 regions in India.

[[DOC File , 49 KB - publichealth_v6i4e23083_app2.doc](#)]

References

1. Oksanen A, Kaakinen M, Latikka R, Savolainen I, Savela N, Koivula A. Regulation and Trust: 3-Month Follow-up Study on COVID-19 Mortality in 25 European Countries. *JMIR Public Health Surveill* 2020 Apr 24;6(2):e19218 [[FREE Full text](#)] [doi: [10.2196/19218](https://doi.org/10.2196/19218)] [Medline: [32301734](https://pubmed.ncbi.nlm.nih.gov/32301734/)]
2. Al-Tawfiq JA, Leonardi R, Fasoli G, Rigamonti D. Prevalence and fatality rates of COVID-19: What are the reasons for the wide variations worldwide? *Travel Med Infect Dis* 2020 May;35:101711 [[FREE Full text](#)] [doi: [10.1016/j.tmaid.2020.101711](https://doi.org/10.1016/j.tmaid.2020.101711)] [Medline: [32360326](https://pubmed.ncbi.nlm.nih.gov/32360326/)]

3. Rubino S, Kelvin N, Bermejo-Martin JF, Kelvin D. As COVID-19 cases, deaths and fatality rates surge in Italy, underlying causes require investigation. *J Infect Dev Ctries* 2020 Mar 31;14(3):265-267 [FREE Full text] [doi: [10.3855/jidc.12734](https://doi.org/10.3855/jidc.12734)] [Medline: [32235086](https://pubmed.ncbi.nlm.nih.gov/32235086/)]
4. Khafaie MA, Rahim F. Cross-Country Comparison of Case Fatality Rates of COVID-19/SARS-COV-2. *Osong Public Health Res Perspect* 2020 Apr;11(2):74-80 [FREE Full text] [doi: [10.24171/j.phrp.2020.11.2.03](https://doi.org/10.24171/j.phrp.2020.11.2.03)] [Medline: [32257772](https://pubmed.ncbi.nlm.nih.gov/32257772/)]
5. Parczewski M, Ciechanowicz A. Molecular epidemiology of SARS CoV-2: a review of current data on genetic variability of the virus. *Pol Arch Intern Med* 2020 Aug 11:11 [FREE Full text] [doi: [10.20452/pamw.15550](https://doi.org/10.20452/pamw.15550)] [Medline: [32785209](https://pubmed.ncbi.nlm.nih.gov/32785209/)]
6. Rajgor DD, Lee MH, Archuleta S, Bagdasarian N, Quek SC. The many estimates of the COVID-19 case fatality rate. *The Lancet Infectious Diseases* 2020 Jul;20(7):776-777. [doi: [10.1016/s1473-3099\(20\)30244-9](https://doi.org/10.1016/s1473-3099(20)30244-9)]
7. Khalatbani-Soltani S, Cumming RG, Delpierre C, Kelly-Irving M. Importance of collecting data on socioeconomic determinants from the early stage of the COVID-19 outbreak onwards. *J Epidemiol Community Health* 2020 Aug 08;74(8):620-623 [FREE Full text] [doi: [10.1136/jech-2020-214297](https://doi.org/10.1136/jech-2020-214297)] [Medline: [32385126](https://pubmed.ncbi.nlm.nih.gov/32385126/)]
8. Harper CA, Satchell LP, Fido D, Latzman RD. Functional Fear Predicts Public Health Compliance in the COVID-19 Pandemic. *Int J Ment Health Addict* 2020 Apr 27:1-14 [FREE Full text] [doi: [10.1007/s11469-020-00281-5](https://doi.org/10.1007/s11469-020-00281-5)] [Medline: [32346359](https://pubmed.ncbi.nlm.nih.gov/32346359/)]
9. Zhang CH, Schwartz GG. Spatial Disparities in Coronavirus Incidence and Mortality in the United States: An Ecological Analysis as of May 2020. *J Rural Health* 2020 Jun 16;36(3):433-445 [FREE Full text] [doi: [10.1111/jrh.12476](https://doi.org/10.1111/jrh.12476)] [Medline: [32543763](https://pubmed.ncbi.nlm.nih.gov/32543763/)]
10. Dong E, Du H, Gardner L. An interactive web-based dashboard to track COVID-19 in real time. *The Lancet Infectious Diseases* 2020 May;20(5):533-534. [doi: [10.1016/s1473-3099\(20\)30120-1](https://doi.org/10.1016/s1473-3099(20)30120-1)]
11. Pulla P. Covid-19: India imposes lockdown for 21 days and cases rise. *BMJ* 2020 Mar 26;368:m1251. [doi: [10.1136/bmj.m1251](https://doi.org/10.1136/bmj.m1251)] [Medline: [32217534](https://pubmed.ncbi.nlm.nih.gov/32217534/)]
12. Mahajan P, Kaushal J. Epidemic Trend of COVID-19 Transmission in India During Lockdown-1 Phase. *J Community Health* 2020 Dec 23;45(6):1291-1300 [FREE Full text] [doi: [10.1007/s10900-020-00863-3](https://doi.org/10.1007/s10900-020-00863-3)] [Medline: [32578006](https://pubmed.ncbi.nlm.nih.gov/32578006/)]
13. Kumar SU, Kumar DT, Christopher BP, Doss CGP. The Rise and Impact of COVID-19 in India. *Front Med (Lausanne)* 2020 May 22;7:250 [FREE Full text] [doi: [10.3389/fmed.2020.00250](https://doi.org/10.3389/fmed.2020.00250)] [Medline: [32574338](https://pubmed.ncbi.nlm.nih.gov/32574338/)]
14. Goel S, Angeli F, Bhatnagar N, Singla N, Grover M, Maarse H. Retaining health workforce in rural and underserved areas of India: What works and what doesn't? A critical interpretative synthesis. *Natl Med J India* 2016;29(4):212-218 [FREE Full text] [Medline: [28050999](https://pubmed.ncbi.nlm.nih.gov/28050999/)]
15. Andrade C. COVID-19: humanitarian and health care crisis in a third world country. *J Clin Psychiatry* 2020 Apr 14;81(3). [doi: [10.4088/jcp.20com13383](https://doi.org/10.4088/jcp.20com13383)]
16. MoHFW | Home. Ministry of Health and Family Welfare, Government of India. URL: <https://www.mohfw.gov.in> [accessed 2020-08-25]
17. Census of India. Office of the Registrar General and Census Commissioner, India. URL: <https://censusindia.gov.in/> [accessed 2020-08-25]
18. State / UT wise Aadhar Saturation. Unique Identification Authority of India, Government of India. 2020 May 31. URL: <https://uidai.gov.in/images/state-wise-aadhaar-saturation.pdf> [accessed 2020-08-25]
19. NITI Aayog. URL: <https://niti.gov.in> [accessed 2020-08-25]
20. Scully EP, Haverfield J, Ursin RL, Tannenbaum C, Klein SL. Considering how biological sex impacts immune responses and COVID-19 outcomes. *Nat Rev Immunol* 2020 Jul 11;20(7):442-447 [FREE Full text] [doi: [10.1038/s41577-020-0348-8](https://doi.org/10.1038/s41577-020-0348-8)] [Medline: [32528136](https://pubmed.ncbi.nlm.nih.gov/32528136/)]
21. Ministry of Social Justice and Empowerment, Government of India. URL: <https://socialjustice.nic.in> [accessed 2020-08-25]
22. Crime in India 2018. National Crime Records Bureau, India. URL: <https://ncrb.gov.in/en/crime-india-2018> [accessed 2020-10-13]
23. Nakamura H, Managi S. Airport risk of importation and exportation of the COVID-19 pandemic. *Transp Policy (Oxf)* 2020 Sep;96:40-47 [FREE Full text] [doi: [10.1016/j.tranpol.2020.06.018](https://doi.org/10.1016/j.tranpol.2020.06.018)] [Medline: [32834679](https://pubmed.ncbi.nlm.nih.gov/32834679/)]
24. How many international airports are in India and which are they? Airports Authority of India. URL: <https://aai.aero/en/content/how-many-international-airports-are-india-and-which-are-they> [accessed 2020-08-25]
25. The India State-Level Disease Burden Initiative. Public Health Foundation of India. 2017. URL: <https://phfi.org/the-work/research/the-india-state-level-disease-burden-initiative/> [accessed 2020-10-13]
26. Li J, He X, Yuan Yuan, Zhang W, Li X, Zhang Y, et al. Meta-analysis investigating the relationship between clinical features, outcomes, and severity of severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) pneumonia. *Am J Infect Control* 2020 Jun 12 [FREE Full text] [doi: [10.1016/j.ajic.2020.06.008](https://doi.org/10.1016/j.ajic.2020.06.008)] [Medline: [32540370](https://pubmed.ncbi.nlm.nih.gov/32540370/)]
27. Sagar R, Dandona R, Gururaj G, Dhaliwal RS, Singh A, Ferrari A, et al. The burden of mental disorders across the states of India: the Global Burden of Disease Study 1990–2017. *The Lancet Psychiatry* 2020 Feb;7(2):148-161. [doi: [10.1016/S2215-0366\(19\)30475-4](https://doi.org/10.1016/S2215-0366(19)30475-4)]
28. Andrade C. The P Value and Statistical Significance: Misunderstandings, Explanations, Challenges, and Alternatives. *Indian J Psychol Med* 2019 Jun 01;41(3):210-215. [doi: [10.4103/ijpsym.ijpsym_193_19](https://doi.org/10.4103/ijpsym.ijpsym_193_19)]

29. Amrhein V, Korner-Nievergelt F, Roth T. The earth is flat ($p > 0.05$): significance thresholds and the crisis of unreplicable research. *PeerJ* 2017;5:e3544 [[FREE Full text](#)] [doi: [10.7717/peerj.3544](https://doi.org/10.7717/peerj.3544)] [Medline: [28698825](https://pubmed.ncbi.nlm.nih.gov/28698825/)]
30. Yu C, Lei Q, Li W, Wang X, Liu W, Fan X, et al. Clinical Characteristics, Associated Factors, and Predicting COVID-19 Mortality Risk: A Retrospective Study in Wuhan, China. *Am J Prev Med* 2020 Aug;59(2):168-175 [[FREE Full text](#)] [doi: [10.1016/j.amepre.2020.05.002](https://doi.org/10.1016/j.amepre.2020.05.002)] [Medline: [32564974](https://pubmed.ncbi.nlm.nih.gov/32564974/)]
31. Saluja M, Pillai D, Jeliua S, Bauddh N, Chandel R. COVID 19 - clinical profile, radiological presentation, prognostic predictors, complications and outcome: a perspective from the Indian subcontinent. *J Assoc Physicians India* 2020;68(7):13-18 [[FREE Full text](#)]
32. Mikami T, Miyashita H, Yamada T, Harrington M, Steinberg D, Dunn A, et al. Risk Factors for Mortality in Patients with COVID-19 in New York City. *J Gen Intern Med* 2020 Jun 30 [[FREE Full text](#)] [doi: [10.1007/s11606-020-05983-z](https://doi.org/10.1007/s11606-020-05983-z)] [Medline: [32607928](https://pubmed.ncbi.nlm.nih.gov/32607928/)]
33. Shahriarirad R, Khodamoradi Z, Erfani A, Hosseinpour H, Ranjbar K, Emami Y, et al. Epidemiological and clinical features of 2019 novel coronavirus diseases (COVID-19) in the South of Iran. *BMC Infect Dis* 2020 Jun 18;20(1):427 [[FREE Full text](#)] [doi: [10.1186/s12879-020-05128-x](https://doi.org/10.1186/s12879-020-05128-x)] [Medline: [32552751](https://pubmed.ncbi.nlm.nih.gov/32552751/)]
34. Gill R, Stewart DE. Relevance of gender-sensitive policies and general health indicators to compare the status of South Asian women's health. *Womens Health Issues* 2011 Jan;21(1):12-18. [doi: [10.1016/j.whi.2010.10.003](https://doi.org/10.1016/j.whi.2010.10.003)] [Medline: [21185987](https://pubmed.ncbi.nlm.nih.gov/21185987/)]
35. Gailits N, Mathias K, Nouvet E, Pillai P, Schwartz L. Women's freedom of movement and participation in psychosocial support groups: qualitative study in northern India. *BMC Public Health* 2019 Jun 10;19(1):725 [[FREE Full text](#)] [doi: [10.1186/s12889-019-7019-3](https://doi.org/10.1186/s12889-019-7019-3)] [Medline: [31182064](https://pubmed.ncbi.nlm.nih.gov/31182064/)]
36. Xie Y, You Q, Wu C, Cao S, Qu G, Yan X, et al. Impact of Cardiovascular Disease on Clinical Characteristics and Outcomes of Coronavirus Disease 2019 (COVID-19). *Circ J* 2020;84(8):1277-1283. [doi: [10.1253/circj.cj-20-0348](https://doi.org/10.1253/circj.cj-20-0348)]
37. Zheng Z, Peng F, Xu B, Zhao J, Liu H, Peng J, et al. *J Infect* 2020 Aug;81(2):e16-e25 [[FREE Full text](#)] [doi: [10.1016/j.jinf.2020.04.021](https://doi.org/10.1016/j.jinf.2020.04.021)] [Medline: [32335169](https://pubmed.ncbi.nlm.nih.gov/32335169/)]
38. Iaccarino G, Grassi G, Borghi C, Ferri C, Salvetti M, Volpe M, et al. Age and Multimorbidity Predict Death Among COVID-19 Patients. *Hypertension* 2020 Aug;76(2):366-372. [doi: [10.1161/hypertensionaha.120.15324](https://doi.org/10.1161/hypertensionaha.120.15324)]
39. Barman H, Atici A, Sahin I, Alici G, Aktas Tekin E, Baycan O, et al. Prognostic significance of cardiac injury in COVID-19 patients with and without coronary artery disease. *Coron Artery Dis* 2020 Jun 19:19 [[FREE Full text](#)] [doi: [10.1097/MCA.0000000000000914](https://doi.org/10.1097/MCA.0000000000000914)] [Medline: [32568741](https://pubmed.ncbi.nlm.nih.gov/32568741/)]
40. Prinja S, Gupta R, Bahuguna P, Sharma A, Kumar Aggarwal A, Phogat A, et al. A composite indicator to measure universal health care coverage in India: way forward for post-2015 health system performance monitoring framework. *Health Policy Plan* 2017 Feb 06;32(1):43-56. [doi: [10.1093/heapol/czw097](https://doi.org/10.1093/heapol/czw097)] [Medline: [27497138](https://pubmed.ncbi.nlm.nih.gov/27497138/)]
41. Chatterjee C, Nayak NC, Mahakud J, Chatterjee SC. Factors affecting the choice of health care utilisation between private and public services among the elderly population in India. *Int J Health Plann Manage* 2019 Jan 31;34(1):e736-e751. [doi: [10.1002/hpm.2686](https://doi.org/10.1002/hpm.2686)] [Medline: [30378705](https://pubmed.ncbi.nlm.nih.gov/30378705/)]
42. Wang Z, Tang K. Combating COVID-19: health equity matters. *Nat Med* 2020 Apr 26;26(4):458-458. [doi: [10.1038/s41591-020-0823-6](https://doi.org/10.1038/s41591-020-0823-6)] [Medline: [32284617](https://pubmed.ncbi.nlm.nih.gov/32284617/)]
43. Zang R, Gomez Castro MF, McCune BT, Zeng Q, Rothlauf PW, Sonnek NM, et al. TMPRSS2 and TMPRSS4 promote SARS-CoV-2 infection of human small intestinal enterocytes. *Sci Immunol* 2020 May 13;5(47):eabc3582 [[FREE Full text](#)] [doi: [10.1126/sciimmunol.abc3582](https://doi.org/10.1126/sciimmunol.abc3582)] [Medline: [32404436](https://pubmed.ncbi.nlm.nih.gov/32404436/)]
44. Rajkumar RP. Prior infection with intestinal coronaviruses moderates symptom severity and mortality in patients with COVID-19: A hypothesis and preliminary evidence. *Med Hypotheses* 2020 Oct;143:110116 [[FREE Full text](#)] [doi: [10.1016/j.mehy.2020.110116](https://doi.org/10.1016/j.mehy.2020.110116)] [Medline: [32721808](https://pubmed.ncbi.nlm.nih.gov/32721808/)]
45. Aktas B, Aslim B. Gut-lung axis and dysbiosis in COVID-19. *Turk J Biol* 2020 Jun 21;44(3):265-272 [[FREE Full text](#)] [doi: [10.3906/biy-2005-102](https://doi.org/10.3906/biy-2005-102)] [Medline: [32595361](https://pubmed.ncbi.nlm.nih.gov/32595361/)]

Abbreviations

DALY: disability-adjusted life year

NITI-Aayog: National Institution for Transforming India

Edited by T Sanchez; submitted 01.08.20; peer-reviewed by N Bhatnagar, J Li, D Ikwuka, A Rovetta, A Azzam; comments to author 14.08.20; revised version received 16.09.20; accepted 30.10.20; published 27.11.20.

Please cite as:

Rajkumar RP

The Relationship Between Demographic, Socioeconomic, and Health-Related Parameters and the Impact of COVID-19 on 24 Regions in India: Exploratory Cross-Sectional Study

JMIR Public Health Surveill 2020;6(4):e23083

URL: <http://publichealth.jmir.org/2020/4/e23083/>

doi: [10.2196/23083](https://doi.org/10.2196/23083)

PMID: [33147164](https://pubmed.ncbi.nlm.nih.gov/33147164/)

©Ravi Philip Rajkumar. Originally published in JMIR Public Health and Surveillance (<http://publichealth.jmir.org>), 27.11.2020. This is an open-access article distributed under the terms of the Creative Commons Attribution License (<https://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in JMIR Public Health and Surveillance, is properly cited. The complete bibliographic information, a link to the original publication on <http://publichealth.jmir.org>, as well as this copyright and license information must be included.

Original Paper

Evaluating the Need for Routine COVID-19 Testing of Emergency Department Staff: Quantitative Analysis

Yuemei Zhang¹, MD, MBA; Sheng-Ru Cheng, BSc

¹Department of Anesthesiology and Pain Medicine, University of Washington, Seattle, WA, United States

Corresponding Author:

Sheng-Ru Cheng, BSc

5F, No 14, Ln 126

Guangming Road, Zhudong Township

Hsinchu County, 310

Taiwan

Phone: 886 968200663

Email: rsrcheng9@gmail.com

Abstract

Background: As the number of COVID-19 cases in the US continues to increase and hospitals experience shortage of personal protective equipment (PPE), health care workers have been disproportionately affected. However, since COVID-19 testing is now easily available, there is a need to evaluate whether routine testing should be performed for asymptomatic health care workers.

Objective: This study aimed to provide a quantitative analysis of the predicted impact that regular testing of health care workers for COVID-19 may have on the prevention of the disease among emergency department patients and staff.

Methods: Using publicly available data on COVID-19 cases and emergency department visits, as well as internal hospital staffing information, we developed a mathematical model to predict the impact of periodic COVID-19 testing of asymptomatic staff members of the emergency department in COVID-19-affected regions. We calculated various transmission constants based on the Diamond Princess cruise ship data, used a logistic model to calculate new infections, and developed a Markov model based on the average incubation period for COVID-19.

Results: Our model predicts that after 180 days, with a transmission constant of 1.219×10^{-4} new infections/person², weekly COVID-19 testing of health care workers would reduce new health care worker and patient infections by approximately 3%-5.9%, and biweekly testing would reduce infections in both by 1%-2.1%. At a transmission constant of 3.660×10^{-4} new infections/person², weekly testing would reduce infections by 11%-23% and biweekly testing would reduce infections by 5.5%-13%. At a lower transmission constant of 4.067×10^{-5} new infections/person², weekly and biweekly COVID-19 testing for health care workers would result in an approximately 1% and 0.5%-0.8% reduction in infections, respectively.

Conclusions: Periodic COVID-19 testing for emergency department staff in regions that are heavily affected by COVID-19 or are facing resource constraints may significantly reduce COVID-19 transmission among health care workers and previously uninfected patients.

(*JMIR Public Health Surveill* 2020;6(4):e20260) doi:[10.2196/20260](https://doi.org/10.2196/20260)

KEYWORDS

infectious; diseases; COVID-19; modeling; policy; emergency medicine; healthcare; health policy; screening tests; surveillance screening

Introduction

Although COVID-19 originated as a small cluster of cases restricted to Wuhan, China, in November and December 2019, SARS-CoV-2, the causative virus, has rapidly spread across the globe since then. On March 11, 2020, the World Health Organization officially declared COVID-19 as a pandemic [1].

In the United States, the number of confirmed COVID-19 cases spiked from only 1 case on January 20, 2020, to 6,244,970 confirmed cases and 188,538 deaths as of September 5, 2020 [2]. The state of Washington, where the first American case of COVID-19 was detected, had 77,208 confirmed COVID-19 cases as of April 14, 2020 [3]. Given the rapid spread of COVID-19 and an associated mortality rate of 3.4% [4],

countries like Italy and China have been forced to ration their limited health care resources, and there are concerns that the US may need to do so, as well [5]. Person-to-person transmission by asymptomatic and presymptomatic individuals during the up-to-14 day incubation period [6] may play a significant role in this pandemic [7-10].

Although data on the extent of hospital-acquired COVID-19 cases are unavailable, nosocomial infections have been shown to play a key role in propagating viral transmission in previous coronavirus outbreaks, such as the SARS outbreak in 2003 [11,12]. Because of the risk of exposure to SARS-CoV-2-infected patients and shortage of personal protective equipment (PPE) in the US as well as other countries [13-15], health care workers (HCW) have been disproportionately affected by the COVID-19 pandemic [16-18].

The aim of this study was to provide a quantitative analysis and model for predicting the impact of periodic COVID-19 testing for all emergency room staff as a possible alternate strategy to mitigate disease transmission in the health care setting, especially since PPE supplies are limited.

Methods

Data Sourcing

In order to model a hospital emergency department (ED) and a moderately affected patient population, we chose to base our model on Harborview Medical Center (HMC) and University of Washington Medical Center (UWMC) in King County, WA, because we had access to their ED staffing information. Because HMC and UWMC are two of many hospitals within the region, for the sake of simplicity, we assumed that the entire patient population from both these hospitals essentially lived in King County, WA.

In order to estimate the number of daily ED visits, we used the publicly available University of Washington Medicine Annual Financial Report for the Board of Regents meeting, which reported that 57,516 ED visits to HMC and 28,276 ED visits to UWMC were made during fiscal year 2018 [19]. Next, to

estimate average daily ED visits, we divided this total number by 365 days, because medical emergencies happen daily regardless of holidays. Although it is possible that the rate of ED visits has changed because of COVID-19 symptoms, socio-behavioral changes, and public policies related to the COVID-19 pandemic, this information is currently not available to us.

The HMC ED currently employs 307 full-time HCW; these include 59 emergency medicine (EM) faculty physicians, 48 EM resident physicians, and 200 full-time equivalent registered nurses (RNs) and medical assistants (MAs). The UWMC ED currently employs 176 full-time HCW, including an estimated 44 EM faculty physicians, 28 EM resident physicians, and 104 full-time equivalent RNs and MAs.

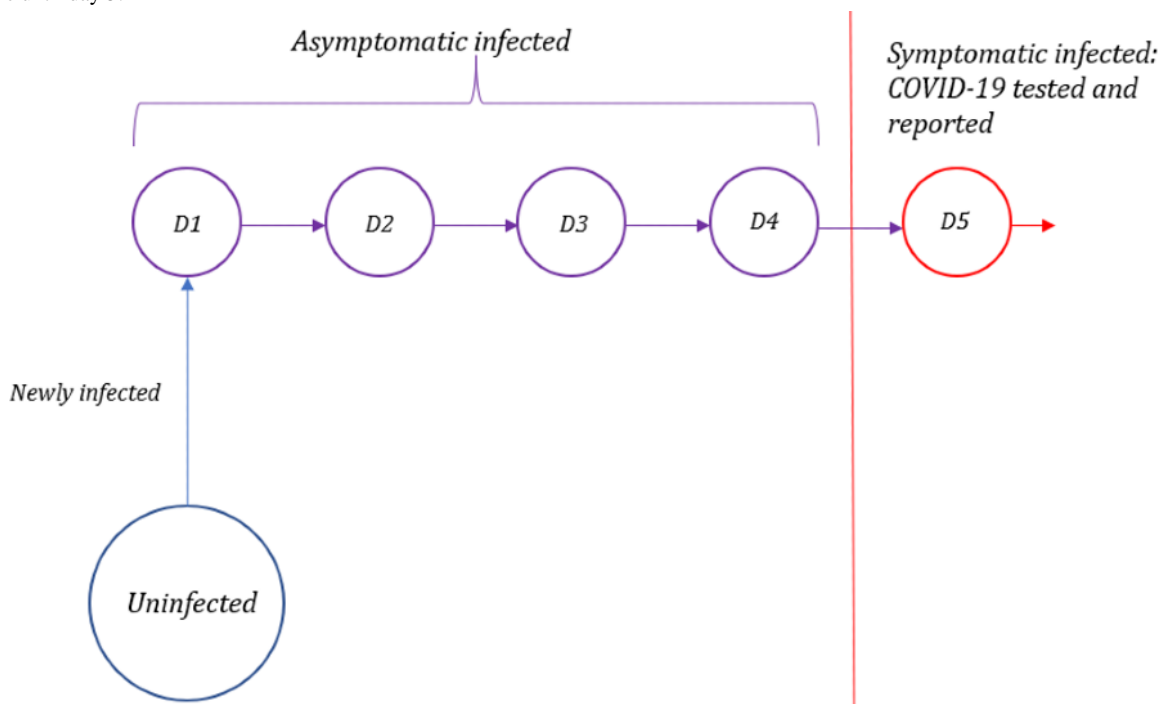
Initial Conditions

Our model is intended to be generalizable to any hospital in the United States; hence, we did not apply hospital-specific policies to our model and instead maintained the same constraints that many other US hospitals have.

Owing to the incubation period of the virus, in addition to the current resource limitations in the US, COVID-19 testing is often not performed until symptoms become evident. Furthermore, laboratory test results for COVID-19 may not be available until patients have left the ED. To estimate the asymptomatic infected population, we examined the number of newly confirmed COVID-19 cases on each date, and we retroactively calculated the daily number of individuals that would have been in the presymptomatic incubation phase. The average incubation period for COVID-19 is approximately 5-6 days [20-22]. For our proposed model, we considered a shorter incubation period of 5 days, implying that symptoms begin on day 5 (Figure 1). Thus, for any time t , the number of asymptomatic infected individuals can be estimated by calculating the sum of new infections that were confirmed on $t+1$ to $t+4$, as follows:



Figure 1. Timeline of infection for confirmed COVID-19 cases. After infection, an individual can transmit the infection to others but does not become symptomatic until day 5.



In other words, if an individual is symptomatic and tests positive for COVID-19 on any of the days between $t+1$ and $t+4$, then this individual can be assumed to be infected but asymptomatic on day t . Using data for King County, WA, collected up to April 5, 2020, we calculated that there were 685 asymptomatic individuals with COVID-19 in King County on April 1, 2020.

In order to determine the total number of infected individuals in King County on any given date, we added the number of publicly reported confirmed cases (as of April 1, 2020) to the number of asymptomatic infected cases that we calculated, from which we then subtracted the number of COVID-19–related deaths. To determine the total uninfected population, we subtracted the number of infected individuals and the number of COVID-19–related deaths from King County’s estimated 2019 population of 2,252,782 [23]. Subsequently, to determine the proportions of the living population that were infected and uninfected, we divided the total infected population and the total uninfected population, respectively, by the total living population.

Since the majority of patients and HCW reside locally, we assumed that their infection statuses would initially also be representative of that of the general population. Thus, to determine our initial values of the number of infected and uninfected patients and HCW/day, we multiplied our calculated proportions with the total number of ED patients/day and the total number of HCW in the ED. For HMC, the initial values thus calculated were 0.21 infected patients/day, 157.36 uninfected patients/day, 0.41 infected HCW, and 306.57 uninfected HCW. For UWMC, the initial values are 0.12 infected patients/day, 77.34 uninfected patients/day, 0.28 infected HCW, and 175.72 uninfected HCW.

Infected HCW were further subdivided into groups based on how long they had been infected. Because asymptomatic

individuals with COVID-19 would continue to remain in the workforce, we also included infected HCW in the health care workforce for days 1-4 of their infection (during this period, they could likely infect other HCW and patients); these infected HCW were removed from the workforce on day 5, when they likely displayed symptoms. For our initial conditions, we uniformly divided the infected HCW into 4 groups: HCW on day 1 of infection (D1), day 2 of infection (D2), day 3 of infection (D3), and day 4 of infection (D4).

Transmission Rate

To investigate the number of preventable infections of HCW from asymptomatic infected patients, we used a logistic model of transmission. The mathematical logistic model used described a dynamic population growth rate that is limited by a certain constraint such as population. In epidemiology, logistic models have been used successfully to model and predict past outbreaks [24,25].

In the equation below, k is the transmission constant, M is the total population size, $\frac{dI}{dt}$ is the rate of change of infected population, and I represents the total infected population, including the asymptomatic infected population.

$$\frac{dI}{dt} = k \cdot I \cdot (M - I) \quad (3)$$

However, since our data is publicly sourced and case reports are available only on a daily basis, we use the discretized form of the logistical model, as follows:

$$I'(t) = k \cdot I(t) \cdot (M - I(t)) \quad (3)$$

$I'(t)$ is the rate of change of the infected population; hence, it can be observed that it is the difference between the infected population at time $t+1$ and time t .

$$I'(t) = I(t+1) - I(t) \quad (4)$$

To calculate the transmission constant, we rearranged the previous equations to the following:

$$k = (I(t+1) - I(t)) / (I(t) \cdot [M - I(t)]) \quad (5)$$

To determine the total infection spread, we need data for some known infected populations, both symptomatic and asymptomatic. For this purpose, we used data extracted from the Diamond Princess cruise ship [6], since the closed quarters of the ship approximate the clinical setting. Due to the isolated nature of the ship, health officials were able to test all individuals onboard the cruise ship for COVID-19, even if no symptoms were evident. Using the data at hand and the above equation, we can readily determine the transmission constant by dividing the number of new cases at time $t+1$ (with time measured in days) by the product of infected population at time t and the uninfected population at time t , which we calculated to be an average of $k = 1.219e-4$ new infections/person².

We know the transmission rate for HCW would likely vary; however, we cannot ascertain whether it would be higher or lower, considering the fact that HCW would likely be in more intimate and close contact with patients than typical interactions between individuals on a cruise ship, and considering factors such as PPE usage by the HCW. Furthermore, the transmission rate varies by department and institution as well. Since we do not have an accurate transmission rate for the resource-limited clinical environment, we decided to model several different scenarios using 3 times the transmission constant ($3.660e-4$ new infections/person²) and one-third the transmission constant ($4.067e-5$ new infections/person²) calculated from the Diamond Princess cruise ship data.

To calculate the number of patient-to-HCW infections, HCW-to-patient infections, and HCW-to-HCW infections

occurring in the ED, we adapted the logistic model to the following equation:

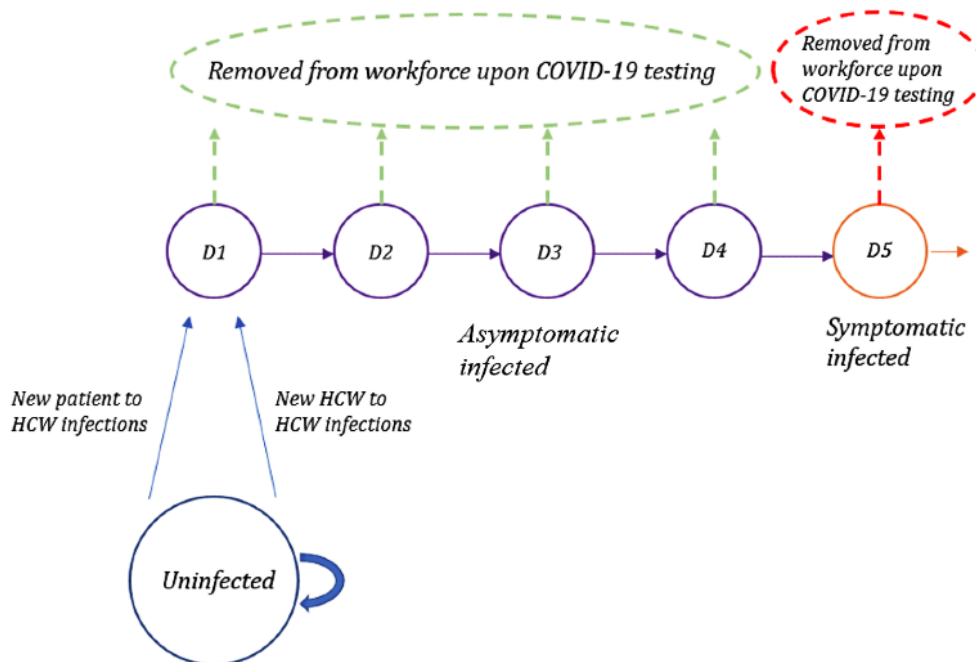
$$I_m'(t) = k \cdot I_n(t) \cdot U_m(t) \quad (6)$$

where $I_m'(t)$ refers to the new infections of a population m , k is the transmission constant, $I_n(t)$ refers to asymptotically infected individuals of the group n transmitting the virus, and $U_m(t)$ refers to uninfected individuals of the group m that is being newly infected. For instance, if $I_m'(t)$ represents new HCW-to-patient infections, then $I_n(t)$ would represent asymptotically infected HCW, and $U_m(t)$ would represent uninfected patients presenting to the ED. These calculations would be repeated in our model for every day.

Assuming adequate inpatient beds are available, a number of patients leave the ED each day—this could either mean they were admitted to the hospital or that they were leaving the institution. On the other hand, a new batch of patients with characteristics representative of the general population would visit the ED each day. Therefore, the initial numbers of uninfected patients and infected patients that we used for our calculations remained constant. In reality, the number of infected patients presenting to the ED may be disproportionately higher than that in the general population, since completely healthy individuals without any acute illness or injury would not visit the ED.

In addition, since the two hospitals were unlikely to have significant changes in their employment in the time period for which we were modeling, we designed a Markov chain to track their infection timelines (Figure 2). New HCW infections constituted the D1 group for the following day, and HCW in D1 would be moved to D2 the following day, HCW in D2 would be moved to D3 the day after, and so on.

Figure 2. Markov chain for HCW. HCW who are uninfected on any given day can either remain uninfected or become newly infected (blue), at which point they would proceed to Day 1 of infection the next day. Individuals who are infected will proceed to the next day of infection (eg, D1, D2) with each passing day. Infected HCW are asymptomatic on days 1-4 (purple). On day 5 of infection, infected individuals begin showing symptoms (orange), at which point they are removed from this workforce. With COVID-19 testing conducted earlier, asymptomatic infected HCW who test positive may also be removed from the health care workforce earlier, on the day when COVID-19 test results are obtained (green). HCW: health care.



Periodic Testing

To simulate periodic COVID-19 testing of all HCW, we assumed COVID-19 test sensitivity of 100%, for the sake of simplicity. In reality, however, test sensitivity is likely to be lower and may vary based on how testing or sample collection is performed; our model can accordingly be adapted for other levels of sensitivity. Currently, there is insufficient data on COVID-19 testing to retrieve information on test sensitivity. On any given day that all HCW are tested, we would manually eliminate (sensitivity)*(number of infected HCW on each day) from each category. With an assumption of 100% sensitivity, this would mean that all infected HCW would be removed from the work force on the day the test was performed (Figure 2). In the case of weekly testing, we started this manual elimination process on day 6, and then repeated this process every 7 days. In the case of biweekly testing, we started the manual elimination process on day 13, and then repeated this process every 14 days.

Results

Our model predicts that over the course of 180 days, 28,364 and 13,945 patients visited the ED in HMC and UWMC,

respectively. Tables 1 and 2 show how the predicted numbers of COVID-19 infections in new patients and HCW vary with different transmission rates and frequencies of COVID-19 testing for HCW at both HMC and UWMC. At the baseline, with a transmission constant of 1.219×10^{-4} new infections/person², without routine COVID-19 testing of HCW, 1,914 HCW infections and 0.985 new patient infections would occur in HMC, and 0.505 HCW infections and 0.223 new patient infections would occur in UWMC. If COVID-19 testing of HCW was performed every 7 days (weekly), 1,802 HCW infections and 0.927 new patient infections would occur in HMC, which would be a 5.9% reduction in both HCW and new patient infections. Similarly, weekly COVID-19 testing for HCW in UWMC would result in 0.489 HCW infections and 0.215 new infections, which would yield a 3.1% reduction. If COVID-19 testing of HCW occurred every 14 days (biweekly), 1,873 HCW infections and 0.964 new patient infections would occur in HMC, which would yield a 2.1% reduction in both HCW and new patient infections. Biweekly COVID-19 testing in UWMC would result in 0.499 HCW infections and 0.220 new patient infections, which would yield a reduction of 1.1%.

Table 1. New patient infections with and without periodic COVID-19 testing for HCW at HMC and UWMC. Predicted numbers of new patient infections with various transmission rates and COVID-19 testing frequencies for HCW after 180 days within the emergency departments of HMC and UWMC. Percentages in parentheses represent the reduction in the number of infections at the given transmission rate with weekly (every 7 days) or biweekly (every 14 days) testing compared to the number of infections with no routine COVID-19 testing for HCW. HCW: health care workers; HMC: Harborview Medical Center; UWMC: University of Washington Medical Center.

COVID-19 transmission rate	COVID-19 testing frequency					
	HMC			UWMC		
	No testing	Weekly testing	Biweekly testing	No testing	Weekly testing	Biweekly testing
1.219e-4 new infections/person ²	0.985	0.927 (5.92%)	0.964 (2.14%)	0.223	0.215 (3.17%)	0.220 (1.14%)
3.660e-4 new infections/person ²	4.475	3.409 (23.81%)	3.906 (12.70%)	0.819	0.726 (11.32%)	0.773 (5.56%)
4.067e-5 new infections/person ²	0.295	0.289 (1.77%)	0.292 (0.85%)	0.0699	0.0693 (1.0%)	0.0696 (0.48%)

Table 2. HCW infections with and without periodic COVID-19 testing for HCW at HMC and UWMC. Predicted numbers of new HCW infections with various transmission rates and COVID-19 testing frequencies for HCW after 180 days within the emergency departments of HMC and UWMC. Percentages in parentheses represent the reduction in the number of infections at the given transmission rate with weekly (every 7 days) or biweekly (every 14 days) testing compared to the number of infections with no routine testing for HCW. HCW: health care workers; HMC: Harborview Medical Center; UWMC: University of Washington Medical Center.

COVID-19 transmission rate	COVID-19 testing frequency					
	HMC			UWMC		
	No testing	Weekly testing	Biweekly testing	No testing	Weekly testing	Biweekly testing
1.219e-4 new infections/person ²	1.914	1.802 (5.86%)	1.873 (2.11%)	0.505	0.489 (3.15%)	0.499 (1.13%)
3.660e-4 new infections/person ²	8.596	6.582 (23.42%)	7.524 (12.47%)	1.850	1.643 (11.21%)	1.748 (5.50%)
4.067e-5 new infections/person ²	0.573	0.563 (1.77%)	0.569 (0.84%)	0.159	0.157 (0.99%)	0.158 (0.47%)

With a transmission constant of 3.660e-4 new infections/person², without routine COVID-19 testing of HCW, 8,596 HCW infections and 4,475 new patient infections would occur in HMC. The corresponding numbers for UWMC would be 1,850 HCW infections and 0,819 new patient infection. If COVID-19 testing of HCW was conducted weekly in HMC, 6,582 HCW infections and 3,409 new patient infections would occur, which is a 23% reduction in both HCW and new patient infections. In UWMC, weekly COVID-19 testing of HCW would result in 1,643 HCW infections and 0,726 new patient infection, which is a reduction of 11.2%. Biweekly COVID-19 testing of HCW (every 14 days) in HMC would result in 7,524 HCW infections and 3,906 new patient infections, which is a 12.47% reduction in HCW infections and a 12.7% reduction in new patient infections. Biweekly testing in UWMC would result in 1,748 HCW infections and 0,773 new patient infection, which is a 5.5% reduction.

For a lower transmission constant of 4.067e-5 new infections/person², 0,573 HCW infections and 0,295 new patient infections would occur in HMC without routine COVID-19 testing of HCW. Similarly, 0,159 HCW infections and 0,0699 new patient infections would occur in UWMC. In the case of weekly COVID-19 testing of HCW in HMC, 0,563 HCW infections and 0,289 new patient infections would occur in HMC, which is a 1.7% reduction in both HCW and new patient infections. In UWMC, 0,157 HCW infections and 0,0693 new patient infections would occur, which is an approximately 1% reduction. In the case of biweekly COVID-19 testing of HCW in HMC, 0,569 HCW infections and 0,292 new patient infections

would occur, which is an approximately 0.85% reduction in HCW infections and new patient infections. In UWMC, this would result in 0,158 HCW infection and 0,0696 new patient infection, which is an approximately 0.47% reduction in potential infections.

Discussion

Our model shows that, within a hospital ED, periodic COVID-19 testing of HCW would reduce the rate of SARS-CoV-2 infection among ED personnel as well as new patients in the ED. As expected, the impact of periodic HCW testing varied with the transmission rate of SARS-CoV-2, with greater benefits observed when the transmission rates were higher.

Our model used the COVID-19 prevalence data for King County, WA, an area which is not as heavily affected by COVID-19 as many other places in the US, considering disease prevalence among patients visiting the ED. A higher COVID-19 prevalence in the patient population may result in higher patient-to-HCW disease transmission rates, in which case, periodic HCW testing would be more beneficial.

A limitation of our model is that we do not know the actual transmission rate in various hospital EDs; furthermore, transmission rates may vary widely between hospitals based on PPE supply, type of interactions with patients, and severity of illness (which also affects the types of procedures and therapies involved), and other factors. Additionally, the transmission rate may be different for different types of HCW; for instance, those

who perform aerosolizing procedures such as intubation may be subject to a higher rate of transmission.

By changing the initial parameters, this model can be adapted for different ED visit rates, ED staffing numbers, levels of infection prevalence, transmission constants, and levels of testing sensitivity. Lower levels of testing sensitivity will lead to decreased utility in periodic HCW testing. In addition, our analysis was performed with the population characteristics of a county that is moderately affected by COVID-19. Currently, many regions of the US have a much higher COVID-19 prevalence, wherein periodic HCW testing would result in a greater potential benefit to prevent HCW infections.

Moreover, due to the current state of COVID-19 testing, US statistics on confirmed COVID-19 cases may not be the most reliable. Per CDC guidelines that were updated on March 24, 2020, at the time of writing this manuscript, laboratory testing for COVID-19 is only indicated for individuals who are not HCW nor first responders and have symptoms that are consistent with COVID-19 [26]. However, many individuals with COVID-19 may be asymptomatic or only have mild symptoms [27]. In addition, shortages of COVID-19 tests may affect the US statistics on COVID-19 cases, making them less reliable [28]. Therefore, the numbers for COVID-19 incidence and

prevalence used in our model, which are based on official reports, may be erroneously low.

Of note, our model only includes ED staff in our numbers, but HCW from other specialties and departments also see patients in the ED. For instance, in many hospitals, non-EM physicians will see inpatient admissions in the ED, specialists may be consulted to see patients in the ED, and surgeons and anesthesiologists may be involved in cases of trauma resuscitations. Additionally, at some teaching hospitals, resident physicians in specialties outside of EM will also have EM rotations.

Given the uncertainty and unavailability of data regarding COVID-19, some of the numbers and factual assumptions in this model may be incorrect, which could affect the model's predictions. To simplify calculations, this model assumes that COVID-19 infections are spread homogeneously throughout the state and that HCW freely interact with patients and all other HCW. Moreover, the model does not consider individual variation in COVID-19 incubation times. Ultimately, this model is intended to be a tool and an approximation, and it can be adapted to different health care settings or regions by varying the initial conditions.

Conflicts of Interest

None declared.

References

1. WHO Director-General's opening remarks at the media briefing on COVID-19 - 11 March 2020. World Health Organization. 2020 Mar 11. URL: <https://www.who.int/dg/speeches/detail/who-director-general-s-opening-remarks-at-the-media-briefing-on-covid-19---11-march-2020> [accessed 2020-03-15]
2. Dong E, Du H, Gardner L. An interactive web-based dashboard to track COVID-19 in real time. *Lancet Infect Dis* 2020 May;20(5):533-534 [FREE Full text] [doi: [10.1016/S1473-3099\(20\)30120-1](https://doi.org/10.1016/S1473-3099(20)30120-1)] [Medline: [32087114](https://pubmed.ncbi.nlm.nih.gov/32087114/)]
3. 2019 Novel Coronavirus Outbreak (COVID-19). Washington State Department of Health. URL: <https://www.doh.wa.gov/Emergencies/COVID19> [accessed 2020-04-14]
4. WHO Director-General's opening remarks at the media briefing on COVID-19 - 3 March 2020. World Health Organization. 2020 Mar 03. URL: <https://www.who.int/dg/speeches/detail/who-director-general-s-opening-remarks-at-the-media-briefing-on-covid-19---3-march-2020> [accessed 2020-03-15]
5. Cha AE. Spiking U.S. coronavirus cases could force rationing decisions similar to those made in Italy, China. *The Washington Post*. 2020 Mar 15. URL: <https://www.washingtonpost.com/health/2020/03/15/coronavirus-rationing-us/> [accessed 2020-03-31]
6. Rapid risk assessment: Novel coronavirus disease 2019 (COVID-19) pandemic: increased transmission in the EU/EEA and the UK – sixth update. European Centre for Disease Prevention and Control. Stockholm: ECDC; 2020 Mar 12. URL: <https://www.ecdc.europa.eu/en/publications-data/rapid-risk-assessment-novel-coronavirus-disease-2019-covid-19-pandemic-increased> [accessed 2020-03-15]
7. Li R, Pei S, Chen B, Song Y, Zhang T, Yang W, et al. Substantial undocumented infection facilitates the rapid dissemination of novel coronavirus (SARS-CoV-2). *Science* 2020 May 01;368(6490):489-493 [FREE Full text] [doi: [10.1126/science.abb3221](https://doi.org/10.1126/science.abb3221)] [Medline: [32179701](https://pubmed.ncbi.nlm.nih.gov/32179701/)]
8. Tindale LC, Stockdale JE, Coombe M, Garlock ES, Lau WYV, Saraswat M, et al. Evidence for transmission of COVID-19 prior to symptom onset. *Elife* 2020 Jun 22;9 [FREE Full text] [doi: [10.7554/eLife.57149](https://doi.org/10.7554/eLife.57149)] [Medline: [32568070](https://pubmed.ncbi.nlm.nih.gov/32568070/)]
9. Ganyani T, Kremer C, Chen D, Torneri A, Faes C, Wallinga J, et al. Estimating the generation interval for coronavirus disease (COVID-19) based on symptom onset data, March 2020. *Euro Surveill* 2020 Apr;25(17) [FREE Full text] [doi: [10.2807/1560-7917.ES.2020.25.17.2000257](https://doi.org/10.2807/1560-7917.ES.2020.25.17.2000257)] [Medline: [32372755](https://pubmed.ncbi.nlm.nih.gov/32372755/)]
10. Liu Y, Centre for Mathematical Modelling of Infectious Diseases nCoV Working Group, Funk S, Flasche S. The contribution of pre-symptomatic infection to the transmission dynamics of COVID-2019. *Wellcome Open Res* 2020 Mar;5:58 [FREE Full text] [doi: [10.12688/wellcomeopenres.15788.1](https://doi.org/10.12688/wellcomeopenres.15788.1)] [Medline: [32685697](https://pubmed.ncbi.nlm.nih.gov/32685697/)]

11. Lee N, Sung JJ. Nosocomial transmission of SARS. *Curr Infect Dis Rep* 2003 Dec;5(6):473-476 [FREE Full text] [doi: [10.1007/s11908-003-0089-4](https://doi.org/10.1007/s11908-003-0089-4)] [Medline: [14642187](https://pubmed.ncbi.nlm.nih.gov/14642187/)]
12. Nishiyama A, Wakasugi N, Kirikae T, Quy T, Ha LD, Ban VV, et al. Risk factors for SARS infection within hospitals in Hanoi, Vietnam. *Jpn J Infect Dis* 2008 Sep;61(5):388-390 [FREE Full text] [Medline: [18806349](https://pubmed.ncbi.nlm.nih.gov/18806349/)]
13. Cranley E. A Chinese official warned of a shortage of protective masks and suits amid the Wuhan coronavirus outbreak. *Business Insider* [Internet]. 2020 Jan 26. URL: <https://www.businessinsider.com/chinese-official-protective-mask-and-suit-shortage-wuhan-coronavirus-2020-1> [accessed 2020-04-15]
14. Rappleye H, Lehren A, Strickler L, Fitzpatrick S. 'This system is doomed': Doctors, nurses sound off in NBC News coronavirus survey. *NBC News* [Internet]. 2020 Mar 20. URL: <https://www.nbcnews.com/news/us-news/system-doomed-doctors-nurses-sound-nbc-news-coronavirus-survey-n1164841> [accessed 2020-04-15]
15. Jacobs A, Richtel M, Baker M. 'At war with no ammo': Doctors say shortage of protective gear is dire. *The New York Times* [Internet]. 2020 Mar 19. URL: <https://www.nytimes.com/2020/03/19/health/coronavirus-masks-shortage.html> [accessed 2020-04-15]
16. Gan N, Thomas N, Culver D. Over 1,700 frontline medics infected with coronavirus in China, presenting new crisis for the government. *CNN* [Internet]. 2020 Feb 14. URL: <https://www.cnn.com/2020/02/13/asia/coronavirus-health-care-workers-infected-intl-hnk/index.html> [accessed 2020-04-15]
17. Bernstein L, Boburg S, Sacchetti M, Brown E. Covid-19 hits doctors, nurses and EMTs, threatening health system. *The Washington Post* [Internet]. 2020 Mar 17. URL: https://www.washingtonpost.com/health/covid-19-hits-doctors-nurses-emts-threatening-health-system/2020/03/17/f21147e8-67aa-11ea-b313-df458622c2cc_story.html [accessed 2020-04-15]
18. Woodward A. Several young doctors in China have died of the coronavirus. Medical workers are far more vulnerable to infection than the general population. *Business Insider* [Internet]. 2020 Mar 03. URL: <https://www.businessinsider.com/why-coronavirus-killed-young-chinese-doctors-2020-2> [accessed 2020-04-16]
19. UW Medicine Annual Financial Report - University of Washington Board of Regents February 14, 2019. *UW Medicine*. 2019 Feb 14. URL: <https://s3-us-west-2.amazonaws.com/uw-s3-cdn/wp-content/uploads/sites/12/2019/02/06104924/2019-02-B-6.pdf> [accessed 2020-03-15]
20. Lauer SA, Grantz KH, Bi Q, Jones FK, Zheng Q, Meredith HR, et al. The incubation period of coronavirus disease 2019 (COVID-19) from publicly reported confirmed cases: estimation and application. *Ann Intern Med* 2020 May 05;172(9):577-582. [doi: [10.7326/M20-0504](https://doi.org/10.7326/M20-0504)] [Medline: [32150748](https://pubmed.ncbi.nlm.nih.gov/32150748/)]
21. Backer JA, Klinkenberg D, Wallinga J. Incubation period of 2019 novel coronavirus (2019-nCoV) infections among travellers from Wuhan, China, 20-28 January 2020. *Euro Surveill* 2020 Feb;25(5) [FREE Full text] [doi: [10.2807/1560-7917.ES.2020.25.5.2000062](https://doi.org/10.2807/1560-7917.ES.2020.25.5.2000062)] [Medline: [32046819](https://pubmed.ncbi.nlm.nih.gov/32046819/)]
22. Linton NM, Kobayashi T, Yang Y, Hayashi K, Akhmetzhanov AR, Jung S, et al. Incubation period and other epidemiological characteristics of 2019 novel coronavirus infections with right truncation: a statistical analysis of publicly available case data. *J Clin Med* 2020 Feb 17;9(2) [FREE Full text] [doi: [10.3390/jcm9020538](https://doi.org/10.3390/jcm9020538)] [Medline: [32079150](https://pubmed.ncbi.nlm.nih.gov/32079150/)]
23. QuickFacts: King County, Washington; Washington. United States Census Bureau. URL: <https://www.census.gov/quickfacts/fact/table/kingcountywashington.WA/PST045219> [accessed 2020-04-27]
24. Liang K. Mathematical model of infection kinetics and its analysis for COVID-19, SARS and MERS. *Infect Genet Evol* 2020 Aug;82:104306 [FREE Full text] [doi: [10.1016/j.meegid.2020.104306](https://doi.org/10.1016/j.meegid.2020.104306)] [Medline: [32278147](https://pubmed.ncbi.nlm.nih.gov/32278147/)]
25. Hsieh Y, Lee J, Chang H. SARS epidemiology modeling. *Emerg Infect Dis* 2004 Jun;10(6):1165-7; author reply 1167-8 [FREE Full text] [doi: [10.3201/eid1006.031023](https://doi.org/10.3201/eid1006.031023)] [Medline: [15224675](https://pubmed.ncbi.nlm.nih.gov/15224675/)]
26. Evaluating and testing persons for coronavirus disease 2019 (COVID-19). Centers for Disease Control and Prevention. 2020 Mar 14. URL: <https://web.archive.org/web/20200317005410/https://www.cdc.gov/coronavirus/2019-ncov/hcp/clinical-criteria.html>
27. Bendix A. South Korea has tested 140,000 people for the coronavirus. That could explain why its death rate is just 0.6% — far lower than in China or the US. *Business Insider* [Internet]. 2020 Mar 05. URL: <https://www.businessinsider.com/south-korea-coronavirus-testing-death-rate-2020-3> [accessed 2020-04-27]
28. Belmonte A. 'Don't believe the numbers you see?': Johns Hopkins professor says up to 500,000 Americans have coronavirus. *Yahoo Finance* [Internet]. 2020 Mar 13. URL: <https://finance.yahoo.com/news/marty-makary-on-coronavirus-in-the-us-183558545.html> [accessed 2020-04-27]

Abbreviations

- ED:** emergency department
- EM:** emergency medicine
- HCW:** health care workers
- MA:** medical assistant
- RN:** registered nurse
- SARS:** severe acute respiratory syndrome

PPE: personal protective equipment

Edited by T Sanchez; submitted 18.05.20; peer-reviewed by M Nasiri, M Adenomon; comments to author 06.08.20; revised version received 27.09.20; accepted 12.10.20; published 03.12.20.

Please cite as:

Zhang Y, Cheng SR

Evaluating the Need for Routine COVID-19 Testing of Emergency Department Staff: Quantitative Analysis

JMIR Public Health Surveill 2020;6(4):e20260

URL: <http://publichealth.jmir.org/2020/4/e20260/>

doi: [10.2196/20260](https://doi.org/10.2196/20260)

PMID: [33052873](https://pubmed.ncbi.nlm.nih.gov/33052873/)

©Yuemei Zhang, Sheng-Ru Cheng. Originally published in JMIR Public Health and Surveillance (<http://publichealth.jmir.org>), 03.12.2020. This is an open-access article distributed under the terms of the Creative Commons Attribution License (<https://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in JMIR Public Health and Surveillance, is properly cited. The complete bibliographic information, a link to the original publication on <http://publichealth.jmir.org>, as well as this copyright and license information must be included.

Original Paper

Clinical Characteristics and Outcomes of Patients With Diabetes Admitted for COVID-19 Treatment in Dubai: Single-Centre Cross-Sectional Study

Rahila Bhatti^{1*}, MRCP; Amar Hassan Khamis^{2*}, PhD; Samara Khatib¹, MD; Seemin Shiraz¹, MRCP; Glenn Matfin^{1,2}, MBChB

¹Department of Endocrinology, Mediclinic Parkview Hospital, Dubai, United Arab Emirates

²Department of Medicine, Mohammed Bin Rashid University of Medicine and Health Sciences, Dubai, United Arab Emirates

*these authors contributed equally

Corresponding Author:

Rahila Bhatti, MRCP

Department of Endocrinology

Mediclinic Parkview Hospital

3 Umm Suqeim

Al Barsha South 1

Dubai

United Arab Emirates

Phone: 971 505290575

Email: rsbhatti91@hotmail.com

Abstract

Background: Recent studies have shown that diabetes is a major risk factor that contributes to the severity of COVID-19 and resulting mortality. Poor glycaemic control is also associated with poor patient outcomes (eg, hospitalization and death).

Objective: This study aimed to describe the clinical characteristics and outcomes of patients with diabetes who were admitted to our hospital for COVID-19 treatment.

Methods: This cross-sectional, observational study comprised patients with diabetes admitted with COVID-19 to Mediclinic Parkview Hospital in Dubai, United Arab Emirates, from March 30 to June 7, 2020. We studied the differences among characteristics, length of hospital stay, diabetes status, comorbidities, treatments, and outcomes among these patients.

Results: Of the cohort patients, 25.1% (103/410) had coexistent diabetes or prediabetes. These patients represented 17 different ethnicities, with 59.2% (61/103) from Asian countries and 35% (36/103) from Arab countries. Mean patient age was 54 (SD 12.5) years, and 66.9% (69/103) of patients were male. Moreover, 85.4% (88/103) of patients were known to have diabetes prior to admission, and 14.6% (15/103) were newly diagnosed with either diabetes or prediabetes at admission. Most cohort patients had type 2 diabetes or prediabetes, and only 2.9% (3/103) of all patients had type 1 diabetes. Furthermore, 44.6% (46/103) of patients demonstrated evidence suggesting good glycaemic control during the 4-12 weeks prior to admission, as defined arbitrarily by admission hemoglobin A_{1c} level <7.5%, and 73.8% (76/103) of patients had other comorbidities, including hypertension, ischemic heart disease, and dyslipidemia. Laboratory data (mean and SD values) at admission for patients who needed ward-based care versus those who needed intensive care were as follows: fibrinogen, 462.8 (SD 125.1) mg/dL vs 660.0 (SD 187.6) mg/dL; D-dimer, 0.7 (SD 0.5) µg/mL vs 2.3 (SD 3.5) µg/mL; ferritin, 358.0 (SD 442.0) mg/dL vs 1762.4 (SD 2586.4) mg/dL; and C-reactive protein, 33.9 (SD 38.6) mg/L vs 137.0 (SD 111.7) mg/L. Laboratory data were all significantly higher for patients in the intensive care unit subcohort ($P<.05$). The average length of hospital stay was 14.55 days for all patients, with 28.2% (29/103) of patients requiring intensive care. In all, 4.9% (5/103) died during hospitalization—all of whom were in the intensive care unit.

Conclusions: Majority of patients with diabetes or prediabetes and COVID-19 had other notable comorbidities. Only 4 patients tested negative for COVID-19 RT-PCR but showed pathognomonic changes of COVID-19 radiologically. Laboratory analyses revealed distinct abnormal patterns of biomarkers that were associated with a poor prognosis: fibrinogen, D-dimer, ferritin, and C-reactive protein levels were all significantly higher at admission in patients who subsequently needed intensive care than in those who needed ward-based care. More studies with larger sample sizes are needed to compare data of COVID-19 patients admitted with and without diabetes within the UAE region.

KEYWORDS

Diabetes; COVID-19; characteristic; outcome; chronic condition; cross-sectional

Introduction

The burden of COVID-19, caused by the novel SARS-CoV-2, has been increasing worldwide. The World Health Organization declared COVID-19 a pandemic on March 11, 2020 [1]. As of October 6, 2020, a total of 99,733 COVID-19 cases have been reported in the United Arab Emirates with 429 COVID-19-related deaths [2].

Recent studies have suggested that diabetes is a major risk factor contributing to the severity of COVID-19 and resulting mortality [3]. For instance, a meta-analysis of 7 trials in China reported that 9.7% (153/1576) patients with COVID-19 had diabetes [4]. Diabetes is also considered a major risk factor for the development of severe pneumonia and clinical course resulting from COVID-19, and it is reported in approximately 20%-30% of such patients [5]. In addition, poor glycemic control, whether related to diabetes or stress hyperglycemia, is known to be associated with poor patient outcomes, including hospitalization and death [6]. A large population-based study in England reported 23,804 COVID-19-related deaths, of which one-third of the patients had diabetes (type 2 diabetes, $n=7466$, 31.4%; type 1 diabetes, $n=365$, 1.5%) [7].

Thus, the aim of this single-center cross-sectional study was to assess the clinical characteristics and outcomes of patients with diabetes admitted to a hospital in Dubai with moderate-to-severe COVID-19.

Methods

Study Design

This is a cross-sectional, observational study of patients with diabetes who were diagnosed with COVID-19 based on laboratory and/or radiological findings and admitted to Mediclinic Parkview Hospital, Dubai, United Arab Emirates, between March 30 and June 7, 2020.

Definitions

A diagnosis of COVID-19 was confirmed by a positive COVID-19 reverse transcription-polymerase chain reaction (RT-PCR) test and/or consistent imaging findings from chest radiography or chest high-resolution computed tomography (HRCT), that is, radiological features of COVID-19 that are pathognomonic (eg, ground-glass opacity).

For the purposes of the study, the following definitions were considered:

- Diabetes was confirmed by either prior diagnosis or hemoglobin A_{1c} (HbA_{1c}) $\geq 6.5\%$ at admission.

- Prediabetes was confirmed by either prior diagnosis and/or HbA_{1c}=5.7%–6.4% at admission.
- Uncontrolled diabetes was defined as HbA_{1c} $\geq 7.5\%$ at admission.
- Patients were discharged from the hospital when they were clinically well and tested negative on two consecutive nasopharyngeal swab tests (laboratory tests) for COVID-19 RT-PCR.
- Admission laboratory tests were defined as tests performed within 24 hours of hospital admission.

Data Collection

Data were collected from electronic medical records retrieved using the software Bayanaty (InterSystems IRIS). Information about patients' basic demographics, nationalities, laboratory data, imaging findings (ie, chest radiograph and chest HRCT), and capillary blood glucose test performed at admission was extracted. Ethical approvals were received from the institutional research board of Mediclinic Parkview Hospital and Dubai Scientific Research Ethics Committee, Dubai Health Authority, Dubai, United Arab Emirates.

Statistical Analysis

Statistical analyses were performed using SPSS software, version 25.0 (IBM Corp, released 2019). Frequencies with proportions were reported for categorical variables and mean values with standard deviation (SD) were reported for continuous variables. Mann Whitney test was used and a P value $< .05$ was considered statistically significant.

Results

A total of 103 patients admitted to the hospital with a confirmed COVID-19 diagnosis had diabetes or prediabetes. During the same timeframe, overall, 410 patients with COVID-19 were admitted. Thus, 25.1% (103/410) of all patients admitted with COVID-19 had coexistent diabetes or prediabetes. Moreover, 66.9% (69/103) of the COVID-19 diabetes cohort were male patients. Patients within this study cohort represented 17 different ethnicities, of which 59.2% (61/103) were from Asian countries and 34.9% (36/103) were from Arab countries. The mean patient age was 54 (SD 12.5) years. In all, 73.8% (76/103) of the cohort patients had other comorbidities, including hypertension, ischemic heart disease, dyslipidemia, and chronic kidney disease (Table 1). Moreover, at admission, 9.7% (10/103) of the patients were receiving angiotensin converting enzyme inhibitor-I (ACE-I) treatment and 31.1% (32/103) patients were receiving angiotensin II receptor blocker (ARB) treatment, both of which were continued as per the individual patient's clinical circumstances during admission, with no obvious adverse effects reported.

Table 1. Basic demographics and pre-comorbidities of study patients (n=103).

Study variable	Value
Gender, n (%)	
Male	69 (66.9)
Female	34 (33.0)
Age in years, mean (SD)	54 (12.5)
Nationality, n (%)	
Arab	36 (34.9)
Asian	61 (59.2)
Western	5 (4.9)
African	1 (0.9)
Comorbidities^a (yes: n=76), n (%)	
Hypertension	66 (64.0)
Dyslipidemia	54 (52.4)
Ischemic heart disease	11 (10.6)
Breast cancer	7 (6.8)
Chronic kidney disease	4 (3.9)
Stroke	3 (2.9)
COPD ^b	1 (0.9)
Renal transplant	1 (0.9)
Medications, n (%)	
ACE-I ^c	10 (9.7)
ARB ^d	32 (31.1)

^aMore than one comorbidity was reported for some patients.

^bCOPD: chronic obstructive pulmonary disease.

^cACE-I: angiotensin converting enzyme inhibitor.

^dARB: angiotensin II receptor blocker.

Out of the 103 cohort patients, 3 (2.9%) patients had type 1 diabetes and 90 (87.4%) patients had type 2 diabetes, 6 of whom were newly diagnosed with type 2 diabetes at admission. Moreover, 10 of 103 (9.7%) patients had prediabetes, 9 of whom

were newly diagnosed at admission. Of those patients with a prior diagnosis of diabetes, 8 (7.8%) patients were on a basal insulin regimen and 6 (5.8%) patients were on basal-bolus insulin regimen (Table 2).

Table 2. Diabetes status among cohort patients before they acquired COVID-19 (n=103).

Item	Value, n (%)
Type of diabetes or dysglycemic status	
Type 1	3 (2.9)
Type 2	90 (87.4)
Prediabetes	10 (9.7)
Diabetes and dysglycemic status	
Known	88 (85.4)
Unknown	15 (14.6)
Control of diabetes	
Controlled (HbA _{1c} ^a <7.5%)	46 (44.6)
Not controlled (HbA _{1c} ≥7.5%)	52 (50.4)
Diabetes medications taken prior to admission^b	
Sulphonylurea	17 (16.5)
Metformin	64 (62.1)
Acarbose	1 (0.9)
DDP-4 ^c inhibitor	4 (3.9)
SGLT-2 ^d inhibitor	5 (4.9)
GLP-1 ^e receptor agonist	1 (0.9)
Basal insulin	8 (7.8)
Basal-bolus insulin	6 (5.8)
Insulin dose (units) in 24 h, mean (SD)	73.4 (33.7)

^aHbA_{1c}: hemoglobin A_{1c}.

^bThe same patient could have received more than one medication.

^cDDP-4: dipeptidyl peptidase-4 inhibitor.

^dSGLT-2: sodium-glucose co-transporter-2.

^eGLP-1: glucagon-like peptide 1.

On admission, several laboratory investigations were performed (Table 3). Average random blood glucose was reported to be 10.2 mmol/L. Of the 103 patients; 56 (54.3%) had lymphopenia; 65 (63.1%) had received a confirmed diagnosis of pneumonia based on radiological findings; 38 (36.8%) had a normal chest

radiograph, 14 of whom had confirmed pneumonia on chest HRCT; and 4 tested negative for COVID-19 based on laboratory RT-PCR but had radiologically confirmed COVID-19 pathognomonic changes.

Table 3. Laboratory data of study patients at hospital admission (n=103).

Laboratory test	Value at admission, mean (SD)	Normal range
HbA _{1c} ^a (%)	7.7 (1.6)	<5.6
Random blood glucose (mmol/L)	10.2 (4.2)	3.9-7.7
Hb (g/dL)	12.8 (1.7)	13.0-17.5
White blood cell count (10 ³ /μL)	6.5 (3.1)	4.0-11.0
Lymphocyte count (10 ³ /μL)	1.2 (0.7)	1.0-4.8
Lymphopenia, n (%)	56 (54.3)	N/A ^b
Platelets (10 ³ /μL)	240.4 (85.3)	150-450
Creatinine (μmol/L)	92.7 (48.9)	63.6-110.5
GFR ^c (mL/min/1.73 ²)	82.8 (22.2)	>60
Ferritin (ng/mL)	757.3 (1548.8)	21.8-274.7
Creatine kinase (U/L)	402.2 (1087.6)	30-200
LDH ^d (U/L)	309.3 (228.9)	125-243
Fibrinogen (mg/dL)	529.3 (175.2)	200-400
Procalcitonin (ng/mL)	0.6 (1.2)	0.0-0.5
CRP ^e (mg/L)	64.1 (82.7)	0.0-5.0
D-dimer (μg/mL)	1.1 (2.1)	0.0-0.5

^aHbA_{1c}: hemoglobin A_{1c}.

^bN/A: not applicable.

^cGFR: glomerular filtration rate.

^dLDH: lactate dehydrogenase.

^eCRP: C-reactive protein.

Table 4 outlines emergent treatments used to manage patients with diabetes who were diagnosed with COVID-19 and their related outcomes. Of the 103 cohort patients, 50 (48.5%) patients received glucocorticoids at admission; 63 (61.2%) patients needed insulin at admission, requiring an average of 29.6 units

per 24 h; and 5 (4.9%) patients had documented hypoglycemia (defined as blood glucose level <4 mmol/L) as detected by capillary blood glucose testing during admission (2 patients were on hydroxychloroquine, 4 on insulin, and 1 had end-stage renal disease).

Table 4. Emergent treatment and outcomes for cohort patients (n=103).

Item	Value
Treatments, n (%)	
Glucocorticoids	50 (48.5)
Hydroxychloroquine	82 (79.6)
Antiviral medication: Kaletra (combination lopinavir/rapinavir)	54 (52.4)
Insulin administered on admission, n (%)	
Intravenous insulin	10 (9.7)
Subcutaneous insulin	53 (51.5)
Units of insulin per 24 h, mean (SD)	29.6 (25.6)
Outcomes	
Hypoglycemia, n (%)	
Insulin	5 (4.9)
Hydroxychloroquine	4 (3.8)
End-stage renal disease	2 (1.9)
Required ICU^a, n (%)	
Need ventilation, n (%)	1 (0.9)
Need ECMO ^b , n (%)	29 (28.2)
Need ECMO ^b , n (%)	12 (11.7)
Need ECMO ^b , n (%)	2 (1.9)
Total deaths (all in ICU), n (%)	5 (4.9)

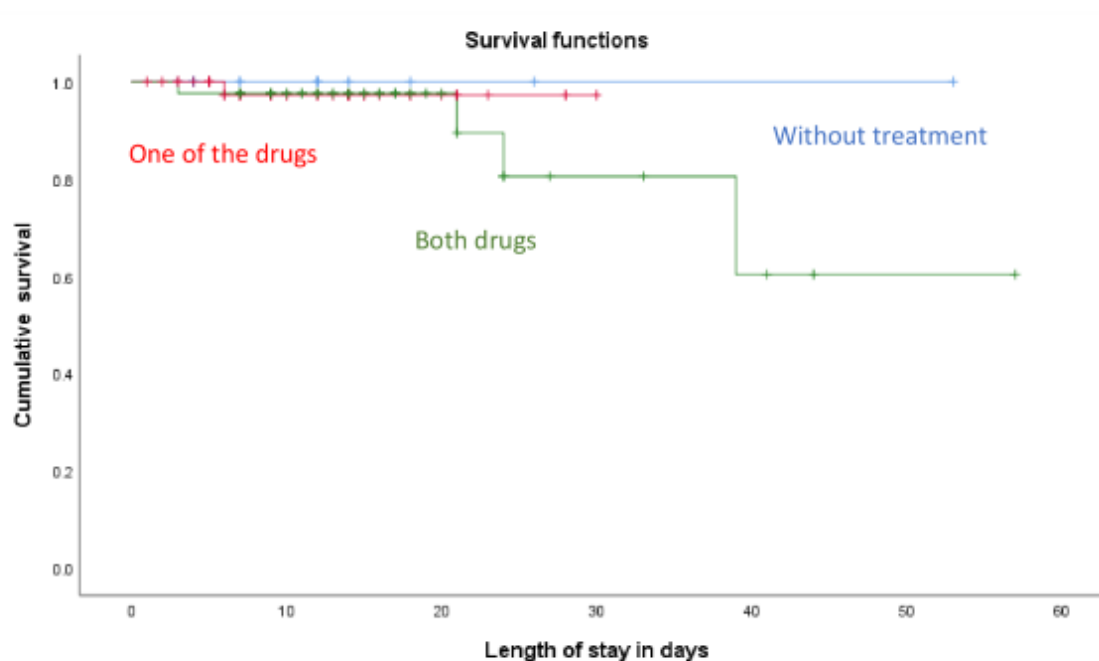
^aICU: intensive care unit.

^bECMO: extracorporeal membrane oxygenation.

Of all the patients (29/103, 28.2%) who were admitted to the intensive care unit (ICU), 21 were from Asian countries and 8, from Arab countries. Furthermore, 22 patients were male. In all, 5 (4.9%) patients (2 males, 3 females) died—all were in the ICU. Four of these patients were of Asian origin, 3 were known to have type 2 diabetes, and 2 had received a new diagnosis of prediabetes on admission. Moreover, 2 of those 5 patients were obese, 1 had end-stage renal disease with known breast cancer,

all 5 had pneumonia, and 4 developed acute respiratory distress syndrome with septic shock. Their average length of stay in the hospital was 18 days.

Kaplan-Meier survival curve (Figure 1) showed that 4 of the 5 deaths that occurred in our study cohort were of patients who received both hydroxychloroquine and glucocorticoid treatment (as might be anticipated based on the severity of disease). The median time of death was 21 (range 3-39) days.

Figure 1. Survival curve generated using Kaplan-Meier method.

Subset Analysis

We performed a subanalysis of the patients' laboratory data on admission and the maximum levels reported during the course of their hospital stay. Fibrinogen, D-dimer, and C-reactive protein (CRP) levels increased significantly during the hospital stay (Table 5).

Among the 103 patients who were admitted with diabetes or prediabetes and were diagnosed with COVID-19, 29 (28.1%) patients needed ICU care; these patients had significantly higher levels of fibrinogen, D-dimer, ferritin, and CRP at admission than did the patients managed by ward-based care (74/103, 71.8%; Table 6).

Table 5. Key biomarkers at admission and maximal levels during hospital stay (n=103).

Biomarkers	Values		
	At admission, mean (SD)	Maximum level during hospital stay, mean (SD)	P value
Fibrinogen (mg/dL)	529.3 (175.2)	550.1 (178.3)	<.001
Procalcitonin (ng/mL)	0.6 (1.2)	1.5 (3.2)	.12
CRP ^a (mg/L)	64.1 (82.7)	92.2 (92.5)	<.001
D-dimer (μg/mL)	1.1 (2.1)	2.0 (3.9)	.01
Ferritin (ng/mL)	757.3 (1548.8)	521.0 (1898.9)	.06

^aCRP: C-reactive protein

Table 6. Key admission biomarkers used as markers of COVID-19 severity (n=103).

Biomarkers	Values		
	Ward-based care (n=74), mean (SD)	ICU ^a (n=29), mean (SD)	P value
Fibrinogen (mg/dL)	462.8 (125.1)	660.0 (187.6)	<.001
Procalcitonin (ng/mL)	0.8 (1.7)	0.6 (1.0)	.31
CRP ^b (mg/L)	33.9 (38.6)	137.0 (111.7)	<.001
D-dimer (µg/mL)	0.7 (0.5)	2.3 (3.5)	.019
Ferritin (ng/mL)	358.0 (442.0)	1762.4 (2586.4)	.01

^aICU: intensive care unit

^bCRP: C-reactive protein

Discussion

In this single-center study conducted in Dubai, 25.1% (103/410) of patients with COVID-19 already had diabetes or prediabetes at admission. Of the study cohort, 14.6% (15/103) received a new diagnosis of diabetes or prediabetes at admission. According to the International Diabetes Federation, the prevalence of diabetes in the United Arab Emirates is 15.4% [8], and our data suggests an overrepresentation of diabetes and prediabetes as risk factors for more severe COVID-19 illness requiring admission.

Most patients with diabetes or prediabetes admitted to hospital for COVID-19 (69/103, 66.9%) were male. This finding is in line with emerging studies that show men with COVID-19 are at a higher risk for developing severe outcomes, including death, than women [3,4,9].

Dubai is a highly multinational society comprising people of more than 200 nationalities. The patients in our study cohort represented 17 different nationalities, of which 59.2% (61/103) were from Asian countries and 34.9% (36/103) were from Arab countries. This finding is also consistent with other studies that suggest that people of Black, Asian, and Minority Ethnic (BAME) populations have increased risk and are predisposed to worse clinical courses and outcomes with COVID-19 than are their Caucasian counterparts [10]. In addition, many individuals of BAME origin are also more likely to have diabetes or prediabetes [11].

Moreover, consistent with recent studies, most patients in our cohort with diabetes or prediabetes and COVID-19 (76/103, 73.8%) also had other notable comorbidities. This finding is consistent with the fact that diabetes and cardiovascular disease are key components of the metabolic syndrome [12]. The metabolic syndrome is also associated with proinflammatory and prothrombotic states, which may have important implications for COVID-19 cases, wherein such complications are especially common and troublesome [13].

In this study, laboratory test results showed that fibrinogen, D-dimer, ferritin, and C-reactive protein (CRP) levels at admission were higher in patients subsequently requiring intensive care treatment. This finding is reflective of the inflammatory cytokine response observed in COVID-19. In addition, measuring admission glucose levels and in-hospital

monitoring are important. Acute hyperglycemia shows upregulation of *ACE2* gene, which facilitates entry of SARS-CoV-2 virus inside the cells. Prolonged hyperglycemia causes downregulation of *ACE2* expression, making the cells vulnerable to the inflammatory effects of the SARS-CoV-2 virus [14]. Thus, performing these laboratory tests at hospital admission may be useful for risk stratification, that is, to determine the potential severity of the disease and guide the level of care that may be required for the patient.

The limitations of our study include the small sample size and retrospective nature of our analysis. Therefore, more studies with larger sample sizes are needed. Another limitation of our study is that there was no control group of patients without diabetes for comparison of results (other than knowing the absolute numbers of total patients admitted with COVID-19 during the same timeframe). In addition, because of the increasing number of new patients presenting with COVID-19 symptoms to our healthcare facility over a short timeframe, data on accurate characterization of overweight or obese status were not available for the majority of our patients; these conditions are thus not reported as comorbidities despite excess bodyweight being related to more severe COVID-19 illness and increased mortality [3,4]. Laboratory investigations such as fibrinogen, D-dimer, ferritin, and CRP levels can help in the initial assessment of severity of disease and subsequent need for ward-based or intensive care.

Conclusion

In this single-center study in Dubai, approximately 25% of patients admitted with COVID-19 also had diabetes or prediabetes. Most of these patients were male and of Asian origin, and 14.6% were newly diagnosed with diabetes or prediabetes upon admission. A majority of these patients (76/100, 73.8%) also had other notable comorbidities. Our comprehensive laboratory analyses revealed distinct abnormal patterns of biomarkers that are associated with a poor prognosis: fibrinogen, D-dimer, ferritin, and CRP levels were all significantly higher at admission in patients who subsequently needed intensive care than in those patients who required ward-based care. In all, 28.2% required ICU admission, of which 5 patients eventually died. More studies with larger sample sizes are needed to compare data of patients with COVID-19 admitted with and without diabetes in the UAE region.

Conflicts of Interest

None declared.

References

1. Cucinotta D, Vanelli M. WHO declares COVID-19 a pandemic. *Acta Biomed* [Internet] 2020 Mar 19;91(1):157-160 [FREE Full text] [doi: [10.23750/abm.v91i1.9397](https://doi.org/10.23750/abm.v91i1.9397)] [Medline: [32191675](https://pubmed.ncbi.nlm.nih.gov/32191675/)]
 2. Eastern Mediterranean Regional Office COVID-19 Dashboard - United Arab Emirates. World Health Organization. 2020. URL: <https://tinyurl.com/vp3vyhz> [accessed 2020-10-06]
 3. Zhou F, Yu T, Du R, Fan G, Liu Y, Liu Z, et al. Clinical course and risk factors for mortality of adult inpatients with COVID-19 in Wuhan, China: a retrospective cohort study. *Lancet* 2020 Mar 28;395(10229):1054-1062. [doi: [10.1016/S0140-6736\(20\)30566-3](https://doi.org/10.1016/S0140-6736(20)30566-3)] [Medline: [32171076](https://pubmed.ncbi.nlm.nih.gov/32171076/)]
 4. Yang J, Zheng Y, Gou X, Pu K, Chen Z, Guo Q, et al. Prevalence of comorbidities and its effects in patients infected with SARS-CoV-2: a systematic review and meta-analysis. *Int J Infect Dis* 2020 May;94:91-95 [FREE Full text] [doi: [10.1016/j.ijid.2020.03.017](https://doi.org/10.1016/j.ijid.2020.03.017)] [Medline: [32173574](https://pubmed.ncbi.nlm.nih.gov/32173574/)]
 5. Bornstein SR, Rubino F, Khunti K, Mingrone G, Hopkins D, Birkenfeld AL, et al. Practical recommendations for the management of diabetes in patients with COVID-19. *Lancet Diabetes Endocrinol* 2020 Jun;8(6):546-550 [FREE Full text] [doi: [10.1016/S2213-8587\(20\)30152-2](https://doi.org/10.1016/S2213-8587(20)30152-2)] [Medline: [32334646](https://pubmed.ncbi.nlm.nih.gov/32334646/)]
 6. Bode B, Garrett V, Messler J, McFarland R, Crowe J, Booth R, et al. Glycemic characteristics and clinical outcomes of COVID-19 patients hospitalized in the United States. *J Diabetes Sci Technol* 2020 Jul;14(4):813-821 [FREE Full text] [doi: [10.1177/1932296820924469](https://doi.org/10.1177/1932296820924469)] [Medline: [32389027](https://pubmed.ncbi.nlm.nih.gov/32389027/)]
 7. Barron E, Bakhai C, Kar P, Weaver A, Bradley D, Ismail H, et al. Type 1 and type 2 diabetes and COVID-19 related mortality in England: a whole population study. SSRN Preprint posted online Jun 19, 2020. [doi: [10.2139/ssrn.3605225](https://doi.org/10.2139/ssrn.3605225)]
 8. IDF MENA Members. International Diabetes Foundation - Middle East and North Africa. URL: <https://idf.org/our-network/regions-members/middle-east-and-north-africa/members/49-united-arab-emirates.html> [accessed 2020-10-06]
 9. Chen N, Zhou M, Dong X, Qu J, Gong F, Han Y, et al. Epidemiological and clinical characteristics of 99 cases of 2019 novel coronavirus pneumonia in Wuhan, China: a descriptive study. *Lancet* 2020 Feb 15;395(10223):507-513 [FREE Full text] [doi: [10.1016/S0140-6736\(20\)30211-7](https://doi.org/10.1016/S0140-6736(20)30211-7)] [Medline: [32007143](https://pubmed.ncbi.nlm.nih.gov/32007143/)]
 10. Khunti K, Singh AK, Pareek M, Hanif W. Is ethnicity linked to incidence or outcomes of covid-19? *BMJ* 2020 Apr 20;369:m1548. [doi: [10.1136/bmj.m1548](https://doi.org/10.1136/bmj.m1548)] [Medline: [32312785](https://pubmed.ncbi.nlm.nih.gov/32312785/)]
 11. Tillin T, Forouhi NG, McKeigue PM, Chaturvedi N, SABRE Study Group. Southall And Brent REvisited: cohort profile of SABRE, a UK population-based comparison of cardiovascular disease and diabetes in people of European, Indian Asian and African Caribbean origins. *Int J Epidemiol* 2012 Feb;41(1):33-42 [FREE Full text] [doi: [10.1093/ije/dyq175](https://doi.org/10.1093/ije/dyq175)] [Medline: [21044979](https://pubmed.ncbi.nlm.nih.gov/21044979/)]
 12. Matfin G. The metabolic syndrome: what's in a name? *Ther Adv Endocrinol Metab* 2010 Apr;1(2):39-45 [FREE Full text] [doi: [10.1177/2042018810374290](https://doi.org/10.1177/2042018810374290)] [Medline: [23148148](https://pubmed.ncbi.nlm.nih.gov/23148148/)]
 13. Wise J. Covid-19 and thrombosis: what do we know about the risks and treatment? *BMJ* 2020 May 21;369:m2058. [doi: [10.1136/bmj.m2058](https://doi.org/10.1136/bmj.m2058)] [Medline: [32439704](https://pubmed.ncbi.nlm.nih.gov/32439704/)]
 14. Bindom SM, Lazartigues E. The sweeter side of ACE2: physiological evidence for a role in diabetes. *Mol Cell Endocrinol* 2009 Apr 29;302(2):193-202 [FREE Full text] [doi: [10.1016/j.mce.2008.09.020](https://doi.org/10.1016/j.mce.2008.09.020)] [Medline: [18948167](https://pubmed.ncbi.nlm.nih.gov/18948167/)]
-

Abbreviations

ACE-I: angiotensin converting enzyme inhibitors
ACE2: angiotensin-converting enzyme 2
ARB: angiotensin II receptor blocker
BAME: Black, Asian, and Minority Ethnic
ECMO: extracorporeal membrane oxygenation
HbA_{1c}: hemoglobin A_{1c}
HRCT: high-resolution computed tomography
ICU: intensive care unit
RT-PCR: reverse transcription polymerase chain reaction

Edited by G Eysenbach; submitted 15.07.20; peer-reviewed by F Chiao, A Azzam; comments to author 27.08.20; revised version received 06.10.20; accepted 25.10.20; published 07.12.20.

Please cite as:

Bhatti R, Khamis AH, Khatib S, Shiraz S, Matfin G

Clinical Characteristics and Outcomes of Patients With Diabetes Admitted for COVID-19 Treatment in Dubai: Single-Centre Cross-Sectional Study

JMIR Public Health Surveill 2020;6(4):e22471

URL: <http://publichealth.jmir.org/2020/4/e22471/>

doi: [10.2196/22471](https://doi.org/10.2196/22471)

PMID: [33284130](https://pubmed.ncbi.nlm.nih.gov/33284130/)

©Rahila Bhatti, Amar Hassan Khamis, Samara Khatib, Seemin Shiraz, Glenn Matfin. Originally published in JMIR Public Health and Surveillance (<http://publichealth.jmir.org>), 07.12.2020. This is an open-access article distributed under the terms of the Creative Commons Attribution License (<https://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in JMIR Public Health and Surveillance, is properly cited. The complete bibliographic information, a link to the original publication on <http://publichealth.jmir.org>, as well as this copyright and license information must be included.

Original Paper

Characterizing Weibo Social Media Posts From Wuhan, China During the Early Stages of the COVID-19 Pandemic: Qualitative Content Analysis

Qing Xu^{1,2,3}, MAS; Ziyi Shen⁴, BS, MS; Neal Shah^{1,2}, BS; Raphael Cuomo^{2,5}, MPH, PhD; Mingxiang Cai^{2,3,4}, BS, MS; Matthew Brown⁶, MPS, PhD; Jiawei Li^{1,2,3,7}, MS; Tim Mackey^{1,2,3,7}, MAS, PhD

¹Department of Healthcare Research and Policy, University of California, San Diego - Extension, La Jolla, CA, United States

²Global Health Policy and Data Institute, San Diego, CA, United States

³S-3 Research LLC, San Diego, CA, United States

⁴Masters Program in Computer Science, Jacobs School of Engineering, University of California, San Diego, La Jolla, CA, United States

⁵Department of Anesthesiology, School of Medicine, University of California, San Diego, La Jolla, CA, United States

⁶US Embassy, National Cancer Institute, National Institutes of Health, Beijing, China

⁷Department of Anesthesiology and Division of Infectious Diseases and Global Public Health, School of Medicine, University of California, San Diego, La Jolla, CA, United States

Corresponding Author:

Tim Mackey, MAS, PhD

Department of Anesthesiology and Division of Infectious Diseases and Global Public Health

School of Medicine

University of California, San Diego

8950 Villa La Jolla Drive

A124

La Jolla, CA, 92037

United States

Phone: 1 951 491 4161

Email: tmackey@ucsd.edu

Abstract

Background: The COVID-19 pandemic has reached 40 million confirmed cases worldwide. Given its rapid progression, it is important to examine its origins to better understand how people's knowledge, attitudes, and reactions have evolved over time. One method is to use data mining of social media conversations related to information exposure and self-reported user experiences.

Objective: This study aims to characterize the knowledge, attitudes, and behaviors of social media users located at the initial epicenter of the outbreak by analyzing data from the Sina Weibo platform in Chinese.

Methods: We used web scraping to collect public Weibo posts from December 31, 2019, to January 20, 2020, from users located in Wuhan City that contained COVID-19-related keywords. We then manually annotated all posts using an inductive content coding approach to identify specific information sources and key themes including news and knowledge about the outbreak, public sentiment, and public reaction to control and response measures.

Results: We identified 10,159 COVID-19 posts from 8703 unique Weibo users. Among our three parent classification areas, 67.22% (n=6829) included news and knowledge posts, 69.72% (n=7083) included public sentiment, and 47.87% (n=4863) included public reaction and self-reported behavior. Many of these themes were expressed concurrently in the same Weibo post. Subtopics for news and knowledge posts followed four distinct timelines and evidenced an escalation of the outbreak's seriousness as more information became available. Public sentiment primarily focused on expressions of anxiety, though some expressions of anger and even positive sentiment were also detected. Public reaction included both protective and elevated health risk behavior.

Conclusions: Between the announcement of pneumonia and respiratory illness of unknown origin in late December 2019 and the discovery of human-to-human transmission on January 20, 2020, we observed a high volume of public anxiety and confusion about COVID-19, including different reactions to the news by users, negative sentiment after being exposed to information, and public reaction that translated to self-reported behavior. These findings provide early insight into changing knowledge, attitudes,

and behaviors about COVID-19, and have the potential to inform future outbreak communication, response, and policy making in China and beyond.

(*JMIR Public Health Surveill* 2020;6(4):e24125) doi:[10.2196/24125](https://doi.org/10.2196/24125)

KEYWORDS

COVID-19; infodemiology; infoveillance; infodemic; Weibo; social media; content analysis; China; data mining; knowledge; attitude; behavior

Introduction

First documented in December 2019, the novel coronavirus is thought to have originated from the city of Wuhan in Hubei Province, China and has quickly emerged as the greatest global public health threat in the last century while also representing a significant test for global preparedness to prevent, diagnose, treat, and contain a highly transmittable disease. At the end of October 2020, this novel coronavirus (COVID-19) pandemic has now impacted 189 countries and geographic territories, with over 40 million confirmed cases and rising, accompanied by over 1 million global deaths [1]. This includes over 91,772 confirmed cases from China [2], with 68,139 cases that originated in Wuhan and 50,340 cases that originated in the initial epicenter of the outbreak in Wuhan City [3,4].

With the COVID-19 outbreak originating and spreading from China, notable given the country's large population, high density of Hubei Province, and the outbreak coinciding with the Lunar New Year period, China implemented a significant public health response including mandated quarantines, community and social isolation, and the construction of two new hospitals [5]. Despite these aggressive measures, at the onset of the outbreak, little was known about the structure, etiology, transmission dynamics, and appropriate public health measures needed to curtail the spread of COVID-19. Much of the fundamental understanding of COVID-19, including the fact that it was a novel coronavirus, emerged throughout the month of January, as the outbreak rapidly spread throughout mainland China.

With the COVID-19 outbreak now a global pandemic, there is a critical need to better understand the origins of the disease and what lessons can be learned from public reaction due to information exposure, or lack thereof, and people's subsequent responses to public health measures implemented. One such approach is the use of data in an electronic medium to supplement traditional epidemiological surveillance measures, also known as "infoveillance" [6]. Data derived from social media platforms represents one of these infoveillance data layers and can be collected and analyzed for the purposes of gauging the public's knowledge, attitudes, and behavior in close to real time. This includes past research leveraging social media to better assess public reaction to outbreaks such as H1N1, Zika virus, and Ebola [7-12].

In the context of the early stages of COVID-19, infoveillance approaches examining popular Chinese social media sites are needed, as most global social media platforms (eg, Twitter, Facebook, Instagram, and Reddit) are blocked in China. As a result, Chinese social media activity primarily occurs on two platforms: WeChat and Sina Weibo. WeChat is a popular

messaging service in China where users can privately communicate with one another, whereas Sina Weibo (commonly referred to as just "Weibo" by its estimated 480 million active users) more closely resembles a microblogging platform with public posts. In 2018, 57% of Weibo users were reported as male and 43% as female [13]. In terms of age, the largest group of users (40%) are aged 23-30 years, followed by users aged 18-22 years (35%), 31-40 years (14%), and 16-17 years (6%); only 5% of users are older than 41 years [13]. These demographics generally skew similar to other popular microblogging platforms such as Twitter whose features and purpose are directly comparable. Specifically, Weibo users can post and interact publicly with information as it arises, representing an accessible and important infoveillance data source to characterize user experiences and conversations during different stages of COVID-19.

Leveraging this data source, other studies have used Weibo posts to characterize conversations and analyze public sentiment, including evaluating whether aspects of the COVID-19 outbreak can be better modeled or characterized [14-21]. One study assessed user-generated discussions on Weibo and found there was public demand for appropriate health resources and equipment during early outbreak stages [22]. Previous studies by our group have identified prevailing COVID-19 themes discussed among Wuhan Weibo users, including uncertainty about the origins of the outbreak, changing concerns about disease transmission characteristics, and varying reactions to the government's outbreak response. Other studies have developed models to better gauge public opinion about COVID-19 among Chinese Weibo users and assess whether adequate warning and attention was given to the outbreak by authorities [17]. Finally, a recent study used infoveillance approaches to track how internet searches and Weibo discussions peaked prior to increased daily case incidence data, and another study used Weibo to identify characteristics of suspected COVID-19 cases and their help-seeking behavior [18,23].

Our study seeks to add to this growing body of literature by leveraging Weibo to better understand Chinese user sentiment and behavior associated with the COVID-19 pandemic. Specifically, the objective of this study is to conduct an in-depth qualitative analysis of Chinese language Weibo posts originating from users located in Wuhan during the early periods of the outbreak to characterize types of news and user knowledge that may have coincided with changes in public sentiment and reaction to the outbreak. This study has an interdisciplinary approach, using methods in computer science, public health, and qualitative analysis.

Methods

Data Collection

To fully explore early COVID-19 outbreak topics and information shared and disseminated by the government, media, and Chinese users in Wuhan, this study first collected social media posts on Sina Weibo and then conducted in-depth qualitative content analysis of all posts collected. Qualitative analysis was used for the purposes of identifying and characterizing user knowledge, attitudes, and impact on behavior from the initial announcement of the pneumonia of unknown origin until the implementation of quarantine in Wuhan City. The overall aim of this study is to identify and characterize key thematic discussions and public reaction located at ground zero of this global pandemic.

Beginning December 31, 2019, we employed an automated web scraper built in the programming language Python to collect public posts on the Weibo platform in the Chinese language (traditional and simplified Chinese). This programming script was set to collect time and geographically filtered data using preset settings available on the advanced search function of the platform. Filters included COVID-19-related keywords, a geographic limitation to collect posts from users located in Wuhan City, and a time period spanning December 31, 2019, to January 20, 2020. Chinese language COVID-19-related keywords were used as filters for this study and included 新型冠状病毒 (novel coronavirus), 武汉肺炎 (Wuhan pneumonia), 不明原因肺炎 (unknown caused pneumonia), and other words associated with the outbreak during its early stages: 华南海鲜市场 (Wuhan Seafood Wholesale Market), and severe acute respiratory syndrome (SARS). Data collected included textual content of post, user and account information, and date and time of post. Messages collected for the purposes of this study were in the public domain and web scraping was done solely for research purposes. Our study does not disclose any personally identifiable information, as we have removed identifiers from our data set and aggregated results. Hence, no ethics approval was required for this study, as we relied on publicly available data, did not include any identifiable information, did not include any private messages between users, and there was no interaction between Weibo users and researchers.

Qualitative Content Analysis

Weibo permits users to post up to 2000 characters with or without images, videos, and other multimedia, and users may also repost messages. These characteristics (particularly the high character count compared to other microblogging platforms) permits a users' post to address multiple topics and have a rich qualitative discussion of issues. To fully capture and accurately classify topics discussed on Weibo related to COVID-19, we manually annotated all posts collected by conducting content analysis of the text in the posts.

The focus of our content analysis was to detect themes associated with knowledge, attitudes, and beliefs of Chinese social media users located in Wuhan in response to exposure to government information sources; news and media outlets; and, specifically, reaction to events that occurred as the outbreak

evolved in the local, national, and global context. Specific themes of interest included conversations and user reactions related to public anxiety, confusion, concerns, and behavior adaptation based on COVID-19-related developments.

Content analysis was conducted using an inductive coding approach primarily because there are few existing qualitative analyses of COVID-19 data in the Chinese language [17,24]. Hence, this open coding approach allowed us to create our own coding classifications based directly on Weibo posts observed. This was accomplished by organizing the data set into binned samples stratified over the entire study period, conducting a first round of content coding based on a generalized sample of the binned data set, creating an initial codebook of parent and subclassifications, rereading the samples and applying codes and classifications, and repeating these steps until all data was coded.

First, two coders (first and second authors) independently used a binary coding approach (ie, relevant vs nonrelevant) to filter posts related to COVID-19 and exclude posts not related to the outbreak. We then used thematic content analysis coding methods, with two coders randomly selecting 200 posts that were then independently coded for parent topic classifications to represent baseline thematic areas or interest and for the purposes of collapsing overlapping or infrequent categories. We then combined the independently coded data sets and created a codebook based on these initial classifications. Coders then independently manually annotated all posts collected in this study and categorized new messages into identified parent topics and existing and new subtopics. Through this process, we selected parent and subtopic classifications, and collapsed infrequent categories by combining related topics, removing duplicate topics, and evaluating thematic concurrence.

We first identified posts for general relevance that we binarily coded as either related or not related to COVID-19 topics. After excluding nonrelevant posts and considering the underlining structure of the Weibo posts, we categorized posts into three broad information source classifications: (1) posts that contained only information from government or news and media sources, (2) posts that contained only user-generated comments, and (3) posts that contained both government/news, and user-generated comments.

We then summarized the content of posts for three parent classification areas initially identified in our random sample of time stratified posts: (1) news and knowledge about the outbreak, (2) public sentiment of users to the outbreak (using an initial set of Chinese language polarity lexicons that were iterated upon, including positive, negative, and neutral [25], and chosen on their basis of relevance to our open inductive coding approach and focus on health topics; see [Textbox 1](#)), and (3) public reaction to control and response measures. Subclassification of topics within these parent classifications were based on the Health Belief Model, where constructs of perceived susceptibility and severity, and cues for action were explored for user-generated posts [26,27]. Before analyzing the text of each post and to account for a single post covering multiple topics, we separated messages into different topic groupings based on the aforementioned parent classifications.

This included separating out content based on the information source.

We also assessed other characteristics of Weibo posts, including temporal variations among topics that occurred over time, and assessed reactions to posts by other users. By analyzing the relative number and content of users' reaction to posts, we could observe variation in the public's attitude from the beginning of the COVID-19 outbreak, as well as measure how these reactions

changed over time specific to news and events that emerged as the outbreak progressed. For both public sentiment and public reaction classifications, temporal stationarity was assessed using the augmented Dickey-Fuller test. For nonstationary categories, regression models were then built to determine statistical significance of linear and exponential relationships, with linear fit (linear R^2) and exponential fit (Cox and Snell R^2) compared for relationships under the threshold $\alpha=.05$.

Textbox 1. List of positive, neutral, and negative lexicons.

Positive lexicon

- Perfect (完美)
- Practical (实用)
- Powerful (强大)
- Good (好)
- Clear (清晰)
- Reliable (可靠的)
- Believable (值得信任的)
- Authoritative (权威性的)
- Confident (自信的/有信心的)
- Fast (快的)
- Safe (安全的)

Neutral lexicon

- Known (知道/听说)
- Suggested (提出的)
- Investigative (调查的)
- Announced (公布)
- Confirmed (确认的)
- Existing (存在)
- Quiet (安静的)
- Unconcerned (不在乎)

Negative lexicon

- Bad (差)
- Poor (烂)
- Awful (坏)
- Disappoint (失望)
- Slow (慢)
- Not work (不行)
- Scared (可怕的)
- Fake (假的)
- Angry (生气的)
- Unclear (模糊的)
- Nervous (紧张的)

Results

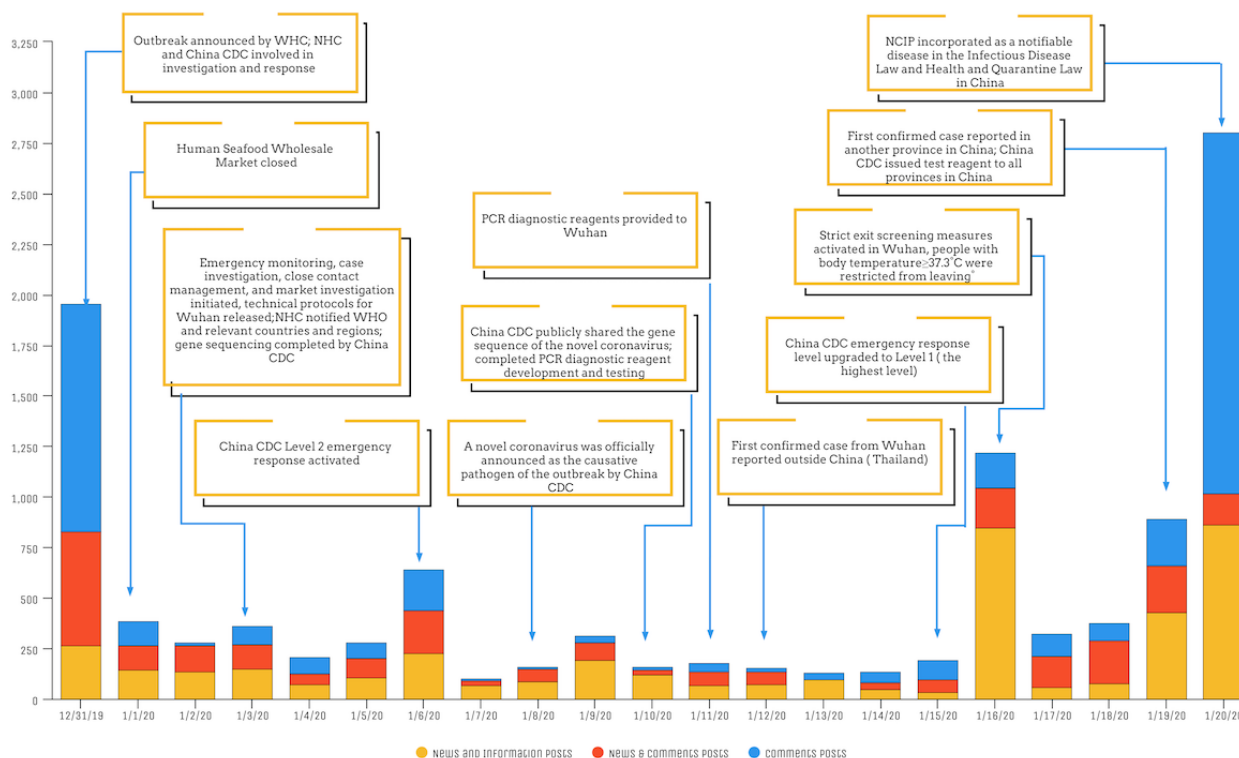
Data

We collected 10,814 Weibo posts located in Wuhan over the 21-day study period. After coding all of these posts independently, the first and second coders achieved a relatively high intercoder reliability score for results ($\kappa=0.892$). Disagreements in coding classification were reviewed by first and second author, and discussed to reach consensus on correct classification. The oldest post collected was dated December 31, 2019, at 12:31 AM (China standard time), and the last post collected was dated January 20, 2020, at 11:00 PM. After manually annotating posts, we filtered out 655 posts (6.06% of

the total data set) not related to the COVID-19 outbreak and retrieved 10,159 posts (93.94%) that we identified as directly related to COVID-19 discussions that comprised of 8703 unique Weibo users.

The largest volume of daily posts ($n=2804$) was on the last day of our study period (January 20, 2020), and the lowest volume ($n=101$) was on January 7, 2020, with the average posts per day at 484 (SD 684.12, median 280). Among the 10,159 relevant posts, 4155 (40.90%) were government information and news and media source only posts, 3330 (32.78%) were user-generated comment posts, and 2674 (26.32%) contained both government and media information, and user-generated content concurrently (see [Figure 1](#)).

Figure 1. The number of Weibo posts related to the COVID-19 outbreak by information source category and with a timeline of events (December 31, 2019, to January 20, 2020). CDC: Center for Disease Control and Prevention; NCIP: novel coronavirus-infected pneumonia; NHC: National Health Commission; PCR: polymerase chain reaction; WHC: Wuhan Health Commission; WHO: World Health Organization.



Results from our content analysis were broken up into findings describing our three parent classification areas: news and knowledge, public sentiment, and public reaction. News and knowledge were generally defined as posts containing COVID-19 outbreak information that originated from different information sources. In contrast, public sentiment was defined as the general attitude and sentiment of users in reaction to news and official government information sources about COVID-19. Finally, public reactions reflected actions or behaviors taken and self-reported by users in response to exposure to COVID-19 information. We noted that the three parent classifications areas often occurred concurrently in a single post, leading to a single Weibo post being classified for multiple parent classifications and subtopics.

News and Knowledge

We retrieved and coded 64 unique news and knowledge posts, and the related subtopics comprised of a total of 6829 posts (67.22% of all 10,159 posts in this study; see [Textbox 2](#) for post examples and [Textbox 3](#) for representative subtopics identified). We then categorized all of these news and knowledge topics into four main thematic areas: (1) news and knowledge related to the causative agent of the disease (including the source of a novel coronavirus, the process to identify the causative agent, transmission pathway, and the naming of a novel virus), (2) epidemiological characteristics of the outbreak (including the number of confirmed cases, patients under intensive care, mortality, suspected cases, cases detected in and out of Wuhan, and cases reported in other countries), (3) official or personal recommended protective measures (including recommendations from the government and personal decisions on seeking

protection from exposure to the virus), and (4) information on the government's actions taken to address the COVID-19 outbreak.

Out of the 6829 posts containing news and information, we identified 18 subtopics from 2997 (43.89%) posts for categories under the first thematic area (causative agent and disease) based on our inductive coding scheme. These posts occurred over 16 days of the total 21-day study period. In the second category

(epidemiological characteristics of the outbreak), we identified 24 topics from 3726 (54.56%) posts identified over a 20-day period. In the third thematic area (effective protective measures), we identified 3 topics from 375 (5.49%) posts, which occurred over only 5 days in our data collection period. Finally, the last thematic area (information on the government's actions toward the COVID-19 outbreak) covered 19 topics from 4155 (37.08%) posts and occurred over a total of 14 days.

Textbox 2. Example language from posts for each study thematic area (with English translation).

News related to the causative agent

- “截至7日21时，专家组认为，本次不明原因的病毒性肺炎病例的病原体初步判定为新型冠状病毒。四种冠状病毒在人群中较为常见，致病性较低，一般仅引起类似普通感冒的轻微呼吸道症状。另外两种冠状病毒——严重急性呼吸综合征冠状病毒和中东呼吸综合征冠状病毒，也就是我们简称的SARS冠状病毒和MERS冠状病毒，可引起严重的呼吸系统疾病。引起此次疫情的新型冠状病毒不同于已发现的人类冠状病毒，对该病毒的深入了解需要进一步科学研究。”
- English translation: “As of 21:00 on the 7th, the expert group believes that the pathogen of this unexplained viral pneumonia case is initially determined to be a new coronavirus. There are four coronaviruses are more common in the population and are less pathogenic, generally causing only mild respiratory symptoms similar to the common cold. The other two coronaviruses—Severe Acute Respiratory Syndrome Coronavirus and Middle East Respiratory Syndrome Coronavirus, which we refer to as SARS coronavirus and MERS coronavirus, can cause severe respiratory diseases. The new coronavirus that caused the outbreak is different from the human coronavirus that has been discovered, and further understanding of the virus requires further scientific research.”

The number of confirmed cases, patients under intensive care, mortality, suspected cases, and cases detected in and out of Wuhan

- “国家、省市专家组对收入医院观察、治疗的患者临床表现、流行病学史、实验室检测结果等进行综合研判，初步诊断有新型冠状病毒感染的肺炎病例41例，其中已出院2例、重症7例、死亡1例，其余患者病情稳定。所有密切接触者739人，其中医务人员419人，均已接受医学观察，没有发现相关病例。”
- English translation: “The national, provincial and municipal expert groups conducted comprehensive research and judgment on the clinical manifestations, epidemiological history, laboratory test results, etc. of patients admitted to the hospital for observation and treatment, and initially diagnosed 41 cases of pneumonia with new coronavirus infection, including 2 discharged, 7 severe cases and 1 death. The remaining patients were in stable condition. All 739 close contacts, including 419 medical personnel, have received medical observations and no related cases have been found.”

Personal recommended protective measures

- “希望大家重视， 重在预防，戴口罩戴口罩戴口罩。早晚各量一次体温。出门戴口罩，勤洗手。咳嗽或打喷嚏时捂住口鼻。将肉蛋彻底做熟。避免与呼吸道患者密切接触。避免近距离接触野生动物或活牲畜。不要随地吐痰。尽量避免人流量密集场所”
- English translation: “I hope everyone pays attention to it, Focus on prevention, wear a mask, wear a mask and wear a mask . Take your temperature in the morning and evening, wear a mask when going out, wash your hands frequently, cover your nose and mouth when coughing or sneezing, cook the meat thoroughly, avoid the respiratory tract Close contact with patients · Avoid close contact with wild animals or live animals · Don't spit anywhere · Try to avoid crowded places”

Government's actions taken to address the COVID-19 outbreak

- “9日，湖北省卫健委称，武汉机场、铁路、公路等多地开始对人群进行体温检测。武汉12306热线表示，旅客进站会有热敏仪器对体温进行检测。”
- English translation: “On the 9th, the Hubei Provincial Health Municipal Commission said that Wuhan Airport, railways, highways and other places began to carry out temperature tests on the crowd. Wuhan 12306 hotline said that passengers will have thermal instruments to detect body temperature when entering the station.”

Textbox 3. Representative topics and subtopics for the news and knowledge category.

Causative agent and disease (December 31, 2019, to January 20, 2020)

- Knowledge about “pneumonia of unclear cause,” “SARS” (severe acute respiratory syndrome), “MERS” (Middle East respiratory syndrome), and coronavirus
- Discussion about human-to-human transmission
- Ruled out seasonal influenza, avian influenza, SARS, MERS, and other common respiratory pathogens from potential causative agents
- Symptoms showed in confirmed cases
- Causative agent of the disease could originate from wildlife
- Causative agent preliminary identification of a novel coronavirus and named as 2019-nCoV
- Family cluster spread

Epidemiological characteristics of outbreak (December 31, 2020, to January 20, 2020)

- Suspected and confirmed cases in and outside of Wuhan
- Discussion about if there is any health worker infection cases reported
- Pneumonia of unknown etiology detected in Wuhan City
- Health status of patients
- Number of people under public health supervision because of contact with confirmed cases
- Death cases reported in Wuhan
- Patients reported having contact with Wuhan Seafood Wholesale Market
- Total number of confirmed cases, total number under intensive care, number of people under public health quarantine, and total number of deaths announced by Wuhan Health Commission

Official or personal recommended effective protective measures (January 4-11, 2020)

- Recommend people to wear masks, avoid crowds, and wash hands
- Traditional Chinese medicine to prevent infection
- Recommend people do not travel to Wuhan

Government’s reaction to COVID-19 outbreak (December 31, 2019, to January 20, 2020)

- Wuhan Central Hospital announced that SARS confirmed cases in the hospital was not true
- Official announcement of updated information related to “pneumonia of unclear cause”
- Mask shortage happened in some areas
- Investigation in Wuhan Seafood Wholesale Market
- World Health Organization advises against the application of any travel or trade restrictions on China
- China and other country governments’ reaction and response toward COVID-19

After identifying all subtopics, we then filtered based on the first date posted and identified four distinct timelines, one for each thematic area. In the first thematic area related to the causative agent and disease source, we observed an evolving timeline where the public gained understanding of what disease they were facing. “Pneumonia of unknown cause” was the first term people used to describe the outbreak, but this changed as the National Health Commission gradually ruled out seasonal influenza, avian influenza, and other common respiratory pathogens including Middle East respiratory syndrome (MERS) and SARS [28]. Finally, on January 9, 2020, the causative agent was identified as a novel coronavirus, though it was not until January 14, 2020, that the World Health Organization (WHO) announced the official name as 2019-nCoV (novel coronavirus)

[29]. This timeline represents a period of initial uncertainty about the disease and its novelty.

Realization that COVID-19 could sustain human-to-human transmission was another critical event that emerged in Weibo posts. In the second timeline related to epidemiological characteristics, in the first week of our study, people who had close contact with the Wuhan Seafood Wholesale Market reported receiving a diagnosis of pneumonia of unknown origin, and the number of confirmed cases reported started increasing, as did the number of reported deaths. As early as day 5, suspected cases began being reported in countries outside of China (in Singapore and South Korea). On January 13, 2020, the first case outside of China was officially reported in Thailand [30]. Domestic spread was also reported, as Beijing and Guangdong started reporting confirmed cases toward the end

of this timeline. Hence, this period represents early recognition of the emergence of a potential pandemic.

In the third timeline related to prevention (also coinciding with greater awareness of the causative agent and regional spread in timelines one and two), on January 5, 2020, the first news information that recommended implementing personal protective measures was detected. Recommendations included posts about wearing masks, avoiding crowds, and washing hands with soap and water or using alcohol-based hand gels. A few posts also appeared in the unofficial media claiming that Chinese traditional medicines could provide effective protection against COVID-19 infection. This period coincides with emerging information about COVID-19 and its spread, and can generally be viewed as the initiation of basic public health measures in an effort to contain what was now a known novel viral disease.

Starting from January 11, 2020, the government started to recommend avoiding travel to Wuhan. In this final timeline, posts showed a series of progressively restrictive policies issued from the government. During this time, the Chinese government also sent experts to Wuhan to help the local authorities investigate the outbreak and to prepare work related to outbreak control. This contrasted with government posts at the beginning of the outbreak that focused on information such as reports of the causative agents, announced closure of the Wuhan Seafood Wholesale Market (which at the time was considered the origin of the virus), and encouraging people to stop spreading unconfirmed information about the outbreak. Hence, this last timeline represents growing recognition of the seriousness of the outbreak and need for government intervention and more stringent control measures.

Finally, among all posts reviewed, we also observed some information that can be categorized as misinformation, particularly in the context of what is known about the disease now. For example, in user discussions about the causative agent, there were posts that believed that the SARS coronavirus was the causative agent. Another misinformation category was detected in user personal recommendations regarding effective disease preventative measures. For example, we detected posts suggesting that using BanLanGen (a traditional medicine) could prevent COVID-19 infection, even though there was no scientific basis at the time for this claim and no new evidence has emerged regarding its use to prevent or treat COVID-19 (also discussed in the *Public Reaction* section). Higher volumes of COVID-19 misinformation were not detected, likely due to these Weibo conversations occurring during the early stages of the pandemic, when there was insufficient basic information

about the disease to generate misinformation or conspiracy-related topics. Content moderation and censorship may have also influenced the possible detection of misinformation on Weibo [31].

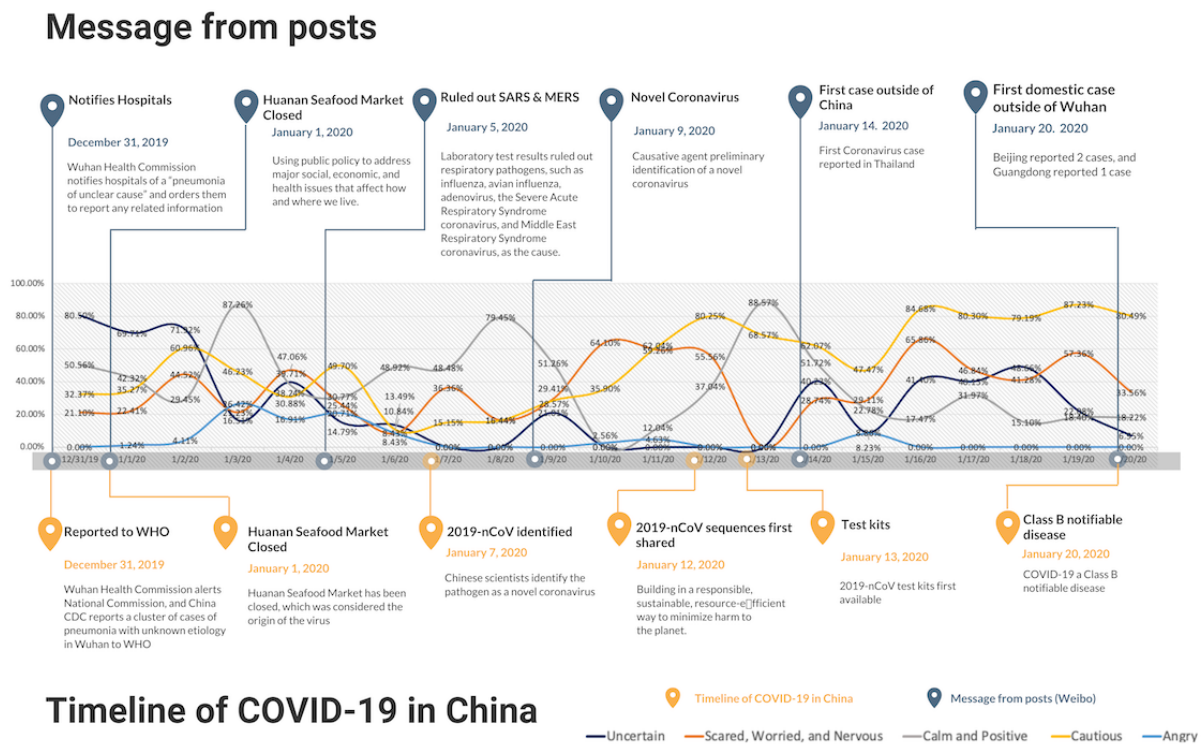
Public Sentiment

Of the total 10,159 posts, we identified 7083 (69.72%) Weibo posts that included user public sentiment (which includes user comments and reactions to news and official reports). For this content, we focused on identification of specific user sentiment and detected 5 general classifications. Most of the user sentiment falls under the general category of anxiety about COVID-19, including expressions of uncertainty; being scared, worried, and nervous; and cautious sentiment. More strongly detected negative sentiment included expressions of anger. In contrast, there was also some general positive sentiment including those who expressed calm and optimistic attitudes in response to the outbreak.

In the general category of anxiety, uncertainty was the dominant sentiment detected. Expressions of uncertainty included questioning whether an infectious disease outbreak was underway, assessing the cause of pneumonia, speculation about the route of transmission, opinions about effectiveness of protective measures, and questioning the source of the outbreak. Of the 7083 posts identified as public sentiment, there were 2519 (35.56%) posts exhibiting uncertain sentiment throughout this 21-day period. The largest volume of these posts ($n=1358$) occurred in the beginning of the study period from January 3 to 13, 2020, when information about COVID-19 was still scarce and developing (see [Figure 2](#)).

Of the 7083 posts identified as public sentiment, the scared, worried, and nervous categories of the general anxiety sentiment included 2337 (32.99%) posts that included user conversations expressing concern and worry about the disease, other people not wearing masks in public areas, nervousness about one's own health conditions, and worrying about family members. This sentiment was persistent from the first day until the last day of our study period but also varied in frequency, with the highest percentage of this sentiment detected on the last day of our study period, and the lowest frequency on January 13, 2020, when no posts for this sentiment were detected. This may be explained by the facts available at the time, including that on or around January 13, the public knew SARS had been ruled out as a potential causative agent; news about eight patients being discharged from a Wuhan hospital was released; and at the time, there was no evidence of human-to-human transmission.

Figure 2. Percentage and classification of public sentiment posts and timeline of events. CDC: Center for Disease Control and Prevention; MERS: Middle East respiratory syndrome; SARS: severe acute respiratory syndrome; WHO: World Health Organization; 2019-nCoV: novel coronavirus.



Of the 7083 posts identified as public sentiment, caution was another anxiety-related sentiment that was detected with a total of 4073 (57.50%) posts and that steadily increased during the 21-day study period examined. In this category, users were cautious and reported that they would need to be prepared if human-to-human transmission of COVID-19 was confirmed. Additionally, after Chinese scientists identified the pathogen as a novel coronavirus, the percentage of posts with cautious attitude began to grow. Generally, as more knowledge about the COVID-19 outbreak and its disease etiology became available, more users expressed cautious sentiment.

In the stronger negative sentiment category of the 7083 posts identified as public sentiment, those expressing anger were detected in only 177 (2.5%) posts, spanning from days 8-21 of the study period. Among these posts, 16 complained about the slow reaction from the Chinese government in response to the outbreak, and 161 posts expressed anger about other people not wearing masks in public areas. Hence, overall criticism of the Chinese government’s COVID-19 response appeared to be minimal, while the vast majority of anger-related posts concerned other members of the public who were perceived as creating higher risk of transmission.

In contrast to the general anxiety and anger-related sentiment of users from the 7083 posts identified as public sentiment, we

also detected 177 (2.50%) posts reflecting positive sentiment about the outbreak. These users expressed calm and optimism about outbreak conditions, including users who were generally not worried about the seriousness of the outbreak, believed the government and current medical technology was sufficient to control the outbreak, and reported being satisfied with the level of transparency of the Chinese government and its outbreak response. Overall, positive sentiment posts were much lower in volume compared to another user sentiment detected.

Among these sentiment categories, statistically significant stationarity over time was observed for percentage of posts in the “calm and optimistic” category ($P<.0001$) and the “angry” category ($P<.0001$; see Table 1). Percentage of posts in the “cautious” category exhibited significant linear and exponential relationships, with exponential fit appearing to be slightly better than linear fit (R^2 : 0.55 vs 0.50). Percentage of posts in the “uncertain” category exhibited a significant exponential trend ($R^2=0.32$) but not a linear trend. Though nonstationary, percentage of posts in the “scared, worried, and nervous” category exhibited neither linear nor exponential significant trends. These results indicate that people in Wuhan became dramatically more cautious and consistently less uncertain during this 21-day period.

Table 1. Results of eight sets of regression models, corresponding to each of the observed attitudes and reactions from Weibo posts, with each set containing a linear model and an exponential model.

Dependent variable	Independent variable	Posts, n	Linear			Exponential ^a		
			β	<i>P</i> value	<i>R</i> ²	<i>b</i>	<i>P</i> value	<i>R</i> ²
Uncertain (%)	Date	21	-0.0145	.12	0.12	-0.2260	.004 ^b	0.32
Scared (%)	Date	21	0.0104	.11	0.12	0.0286	.13	0.59
Cautious (%)	Date	21	0.2819	<.001	0.50	0.0596	<.001	0.54
Mask (%)	Date	21	0.0168	.07	0.16	0.0372	.04	0.18
Cancel (%)	Date	21	-0.0001	.98	<0.01	-0.0034	.95	<0.01
Self-treatment (%)	Date	21	-0.0003	.20	0.08	-0.1135	.42	<0.01
Normal (%)	Date	21	-1.2999	.99	<0.01	-0.0006	>.99	<0.01
Evacuate (%)	Date	21	-0.0006	.44	0.03	-0.1647	.09	0.12

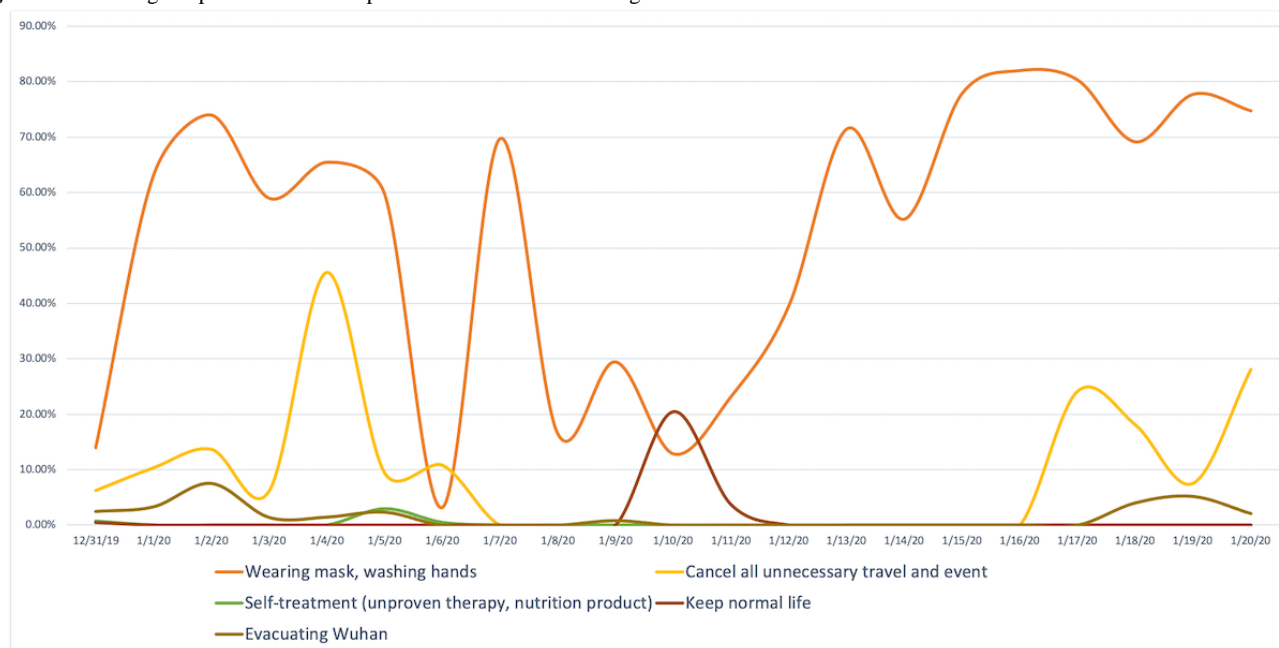
^aThe exponential coefficient and *P* values were provided for the *b* coefficient in the $Y=a+b^x$ equation, and exponential *R*² values were computed as Cox and Snell *R*².

^bItalics represent statistically significant *P* values.

Public Reaction

In the last category of post characteristics, of the total 10,159 posts, we detected 4863 (47.87%) posts that self-reported user reaction to COVID-19-related information, which also led to identification of five different types of resultant behaviors reported by users (see Figure 3). Reactions included self-reporting protective behavioral factors including wearing

masks; washing hands more frequently; and cancelling all unnecessary travel, gatherings, and events. In contrast, some self-reported behavior we detected could be categorized as elevating health risk, including self-treatment with unproven therapy and nutritional products, maintaining preoutbreak lifestyle and habits, and self-evacuation from Wuhan. We noted that some of these reaction themes also occurred concurrently.

Figure 3. Percentage of posts classified as public reaction and their categories.

For example, a total of 3689 posts (75.86% of all public reaction posts) included users reporting their choice to start wearing masks. This behavior also coincided with public announcements, with an increase of approximately 50% in the number of mask-related posts observed 2 days after such recommendations were made. However, on January 6, 2020, the percentage of mask-related posts dropped to 3.13%. Based on our timeline of events, we observed that on January 5, 2020, the Chinese health

commission ruled out SARS and MERS as the causative agent, which could have led to a sense of false security and lower mask use among the public. On January 7, when the causative agent was identified as a novel coronavirus, the percentage of mask posts then rose to 69.70% and continued to fluctuate based on other news events.

The second largest volume of public reaction posts ($n=987$, 20.30% of all reaction posts) was related to canceling

unnecessary travel and events, followed by evacuating Wuhan (n=148, 3.04%), maintaining a normal lifestyle (n=20, 0.41%), and beginning self-treatment (n=19, 0.39%; see [Textbox 4](#) for examples). These posts evidenced that users not only were exposed to and changed their knowledge, attitudes, and perceptions about the outbreak but also acted upon changing information through different types of behaviors and actions. Some of these reactions could have directly impacted outbreak control measures (eg, traveling when not recommended prior

to an official quarantine, attending public gatherings, and engaging in self-care).

No public reaction category exhibited statistically significant stationarity (see [Table 1](#)). Percentage of posts in the “wearing mask, washing hands” category exhibited a significant exponential trend over time ($R^2=0.19$) but not a linear trend. Other categories did not exhibit significant linear or exponential trends. Over this 21-day period, the Wuhan population appears to have gravitated toward wearing masks and washing hands but not toward other preventative behaviors.

Textbox 4. Example language from posts for each type of behaviors.

Self-reporting protective factors

- Wearing masks and washing hands
 - “除了不传谣不信谣,自己平常多注意少去人多密集的地方,有症状及时就医 老百姓做的还能有啥,难道真要等到武汉封城才开始注意吗?在网上乱猜想还不如多喝热水,多戴口罩,多睡觉!”
 - English translation: “As a normal citizen, there is nothing we can do, except not spreading rumors, not going to crowded, and going to hospital when symptoms shows. Shouldn’t have to wait until the lock down of Wuhan, people will start paying attention? It works better to drink more hot water, wear mask and sleep more rather than making assumption online.”
- Cancelling all unnecessary travel, gatherings, and events
 - “因为武汉新型冠状病毒肺炎,不得不取消回武汉的行程.很久很久没见父母亲人了.突然好难过,退票票的时候没忍住哭了”
 - English translation: “Because of Wuhan's new coronavirus pneumonia, I had to cancel my trip back to Wuhan. I haven't seen my parents and relatives for a long time. Suddenly feeling so sad and couldn't help crying when refunding the ticket.”

Behavior that could elevate health risk

- Self-treatment with unproven therapy and nutritional products
 - “赶紧掏出板蓝根,管他有没有用”
 - English translation: “Find out Banlangen (a traditional Chinese herbal medicine. It has been used for the prevention and treatment of virus-related respiratory diseases such as influenza virus infection [32]. whether it is useful or not.”
- Maintaining preoutbreak lifestyle/habits
 - “病毒也不能阻止我,戴上口罩去跨年”
 - English translation: “The virus can't stop me, put on a mask to go to the New Year celebration.”
- Self-evacuation from Wuhan
 - “火灾+地震+不明原因肺炎,还是逃离武汉吧”
 - English translation: “Fire + earthquake + unknown caused pneumonia, should escape from Wuhan.”

Discussion

Principal Findings

Our study conducts an in-depth qualitative analysis of 10,159 COVID-19 Weibo posts from 8703 unique Sina users located at the initial epicenter of the outbreak, Wuhan City. In these posts, we observed that 67.22% (n=6829) of posts included news and knowledge posts, 69.72% (n=7083) included public sentiment topics, and 47.87% (n=4863) included public reaction and self-reported behavior. Though major thematic issues about the causative agent, epidemiological characteristics of the outbreak, and personal protective measures along with how the Chinese government responded to this novel virus were detected, these topics were not static and changed over time as new

information about COVID-19 emerged and was communicated to the public. Initial uncertainty and changing knowledge, attitudes, and beliefs about COVID-19 also coincided with changes in users’ sentiment and self-reported behaviors that may have acted to mitigate or potentially worsen the spread of the disease.

This study is limited to 21 days of social media posts that occurred at the early stages of the COVID-19 outbreak in Wuhan, China to better understand key topics related to individuals’ awareness, concerns, and reactions to the crisis. Overall, the volume of posts varied throughout the study period, with the largest volume of posts originating from government or news and media only sources. We also observed a high volume of uncertainty sentiment about COVID-19 from Weibo

users in Wuhan, though these expressions of uncertainty varied and gradually cleared with time. We observed different timelines of events that related to specific news and knowledge categories beginning with uncertainty about COVID-19; growing concern of a potential global pandemic; and finally, initial government and public actions to contain the spread of the disease, indicative of an early outbreak public reaction and response.

Specifically, one of the most consequential announcements marked the beginning of the pandemic timeline and occurred on December 31, 2019, when the Wuhan Health Municipal Commission announced the emergence of a pneumonia and respiratory illness of unknown origin, followed by a similar announcement by the WHO 6 days later [33,34]. Following this announcement, several key early outbreak events occurred, including the reporting of the Huanan Seafood Market as the suspected origin of the outbreak, confirmation that the virus was a novel coronavirus, establishment by the Chinese government of public health and sanitation guidelines, and the announcement of human-to-human transmissibility of COVID-19 [35]. All these events appeared to influence the news and information disseminated on Weibo and impacted the public's sentiment and reaction to COVID-19. Our study period ended on another important early outbreak event: the implementation of the quarantine of Wuhan City on January 23, 2020, where we observed a rapid increase in social media conversations but that were not analyzed for this study.

These findings also indicate that the relationship between exposure to news and information also fits well with the agenda-setting theory, which describes how the media stimulates awareness, shapes and filters reality, and sets priorities of the public for salient issues including for public health concerns [36]. In this case, the exposure to changing news and information on Weibo and the ability of these social media users to directly communicate their opinions and behaviors evidenced the complex interaction between the government, media sources, and the public during an early outbreak period. This interaction is supported by past studies that have also found an association with an increase in the volume of social media posts about an outbreak and major news events in past health emergencies [14,37]. Our findings provide further clues about how the public responds to disease outbreak communication and specific events as they unfold, which can increase anxiety and even misplaced optimism about the personal and population health risk of a novel disease. Future work should focus on further adapting the agenda-setting theory to health promotion efforts targeted for outbreak response and that is contextualized for local communities and social media platforms [36].

Importantly, this study provides early insight into COVID-19, the most consequential disease outbreak in the last century, which occurred at a time when global public engagement on social media platforms such as Weibo are at an all-time high. Analyzing social media data can provide valuable insights into a communities' knowledge, concerns, and fears, which can influence individual and population-level behavior—important factors that can have a direct impact on the success or failure of public health interventions aimed at containing the spread of a disease. These findings can also aid in developing communication tools and health promotion activities to help the public better understand transmission risks, correct confusion or misinformation, and educate on social and behavioral risks that may exacerbate spread.

Though our study was limited to Wuhan City and the early stages of the outbreak, these infoveillance insights are salient even now. This includes using this information to better prepare for re-emergence or new waves of COVID-19 in different communities; ensuring appropriate health messaging on new COVID-19 developments such as vaccine and therapeutic deployment; and communicating to the public about ongoing social distancing, quarantining, masking, and reopening recommendations. Hence, the importance of the “infoveillance” field for outbreak detection and monitoring has arguably never been more important, with this study representing one piece of this growing field that can generate closer to real-time public health intelligence from digital data sources. It is our hope that these results can help inform governments and public health stakeholders on strategies to improve outbreak communication for COVID-19 and into the future, in an era where digital platforms are now a dominant source of information and interaction.

Limitations

This study has certain limitations. Our data collection was limited to a single Chinese social media platform and to a specific geographic area. Hence, the findings are in no way generalizable to all COVID-19 social media conversations occurring among Chinese users. Our data collection focused on the early stages of the COVID-19 outbreak. However, during periods of this time frame, the causative agent had not been confirmed, and there was no official name for the disease. Due to this early inconsistency in disease terminology, Weibo users may have used other keywords to describe COVID-19-related conversations or topics that were not collected by this study. Finally, due to possible censorship of social media posts, some Weibo posts may have been deleted before data collection, and these conversations or public sentiment may not have been captured.

Acknowledgments

Data collected on social media platforms is available on request from authors subject to appropriate deidentification.

Authors' Contributions

This manuscript has been seen by all authors, who have approved its content. This piece is not under consideration in any other forum. QX contributed to the conceptualization, methodology, formal analysis, investigation, writing of original draft, and

reviewing and editing. ZS contributed toward the formal analysis and investigation. NS contributed toward the writing of the original draft. RC contributed toward the formal analysis. MC contributed toward the methodology, formal analysis, and investigation. MB contributed toward the methodology, formal analysis, and investigation. JL contributed toward the data curation. TM contributed toward the conceptualization, methodology, formal analysis, investigation, writing of original draft, and reviewing and editing.

Conflicts of Interest

QX, MC, JL, and TKM are employees of the startup company S-3 Research LLC. S-3 Research is a startup funded and currently supported by the National Institutes of Health – National Institute on Drug Abuse through a Small Business Innovation and Research contract for opioid-related social media research and technology commercialization. Author reports no other conflict of interest associated with this manuscript.

References

1. Coronavirus disease (COVID-19) pandemic. World Health Organization. 2020. URL: <https://www.who.int/emergencies/diseases/novel-coronavirus-2019> [accessed 2020-05-06]
2. 新型冠状病毒肺炎疫情分布. Chinese Center for Disease Control and Prevention. 2020. URL: <http://2019ncov.chinacdc.cn/2019-nCoV/> [accessed 2020-05-26]
3. 2020年5月30日湖北省新冠肺炎疫情情况. Wuhan Municipal Health Commission. 2020. URL: http://www.hubei.gov.cn/zhuanti/2020/dqssl/qwtb/202005/t20200531_2372675.shtml [accessed 2020-10-28]
4. 2020年10月25日湖北省新冠肺炎疫情情况. Wuhan Municipal Health Commission. 2020. URL: http://www.hubei.gov.cn/zhuanti/2020/dqssl/qwtb/202010/t20201026_2974983.shtml [accessed 2020-10-28]
5. Wu Z, McGoogan JM. Characteristics of and important lessons from the coronavirus disease 2019 (COVID-19) outbreak in China: summary of a report of 72 314 cases from the Chinese Center for Disease Control and Prevention. *JAMA* 2020 Apr 07;323(13):1239-1242. [doi: [10.1001/jama.2020.2648](https://doi.org/10.1001/jama.2020.2648)] [Medline: [32091533](https://pubmed.ncbi.nlm.nih.gov/32091533/)]
6. Eysenbach G. Infodemiology and infoveillance: framework for an emerging set of public health informatics methods to analyze search, communication and publication behavior on the Internet. *J Med Internet Res* 2009 Mar 27;11(1):e11 [FREE Full text] [doi: [10.2196/jmir.1157](https://doi.org/10.2196/jmir.1157)] [Medline: [19329408](https://pubmed.ncbi.nlm.nih.gov/19329408/)]
7. Chew C, Eysenbach G. Pandemics in the age of Twitter: content analysis of Tweets during the 2009 H1N1 outbreak. *PLoS One* 2010 Nov 29;5(11):e14118 [FREE Full text] [doi: [10.1371/journal.pone.0014118](https://doi.org/10.1371/journal.pone.0014118)] [Medline: [21124761](https://pubmed.ncbi.nlm.nih.gov/21124761/)]
8. Eysenbach G. Infodemiology and infoveillance tracking online health information and cyberbehavior for public health. *Am J Prev Med* 2011 May;40(5 Suppl 2):S154-S158. [doi: [10.1016/j.amepre.2011.02.006](https://doi.org/10.1016/j.amepre.2011.02.006)] [Medline: [21521589](https://pubmed.ncbi.nlm.nih.gov/21521589/)]
9. Kenter W, van Gemert-Pijnen JEWC, Ossebaard HC. Is big data useful for the early detection of zoonotic disease outbreaks? Use of real-time data for the early detection of zoonotic disease epidemics in the Netherlands: a literature review. Submitted for eTELEMED 2014. URL: https://www.researchgate.net/publication/289525075_Is_Big_Data_Useful_for_the_Early_Detection_of_Zoonotic_Disease_Outbreaks
10. Pagliari C, Vijaykumar S. Digital participatory surveillance and the Zika crisis: opportunities and caveats. *PLoS Negl Trop Dis* 2016 Jun;10(6):e0004795 [FREE Full text] [doi: [10.1371/journal.pntd.0004795](https://doi.org/10.1371/journal.pntd.0004795)] [Medline: [27294787](https://pubmed.ncbi.nlm.nih.gov/27294787/)]
11. Mavragani A, Ochoa G. Google Trends in infodemiology and infoveillance: methodology framework. *JMIR Public Health Surveill* 2019 May 29;5(2):e13439 [FREE Full text] [doi: [10.2196/13439](https://doi.org/10.2196/13439)] [Medline: [31144671](https://pubmed.ncbi.nlm.nih.gov/31144671/)]
12. Vorovchenko T, Ariana P, van Loggerenberg F, Amirian P. #Ebola and Twitter. What insights can global health draw from social media? In: Amirian P, Lang T, van Loggerenberg F, editors. *Big Data in Healthcare: Extracting Knowledge From Point-of-Care Machines*. Cham, Switzerland: Springer, Cham; 2017:85-98.
13. 2018微博用户发展报告. WeiBaoGao. 2019. URL: <https://data.weibo.com/report/reportDetail?id=433> [accessed 2020-10-28]
14. Li J, Xu Q, Shah N, Mackey TK. A machine learning approach for the detection and characterization of illicit drug dealers on Instagram: model evaluation study. *J Med Internet Res* 2019 Jun 15;21(6):e13803 [FREE Full text] [doi: [10.2196/13803](https://doi.org/10.2196/13803)] [Medline: [31199298](https://pubmed.ncbi.nlm.nih.gov/31199298/)]
15. Hu Y, Huang H, Chen A, Mao XL. Weibo-COV: a large-scale COVID-19 social media dataset from Weibo. Arxiv. Preprint posted online May 19, 2020.
16. Han X, Wang J, Zhang M, Wang X. Using social media to mine and analyze public opinion related to COVID-19 in China. *Int J Environ Res Public Health* 2020 Apr 17;17(8) [FREE Full text] [doi: [10.3390/ijerph17082788](https://doi.org/10.3390/ijerph17082788)] [Medline: [32316647](https://pubmed.ncbi.nlm.nih.gov/32316647/)]
17. Li L, Zhang Q, Wang X, Zhang J, Wang T, Gao T, et al. Characterizing the propagation of situational information in social media during COVID-19 epidemic: a case study on Weibo. *IEEE Trans Comput Soc Syst* 2020 Apr;7(2):556-562. [doi: [10.1109/tcss.2020.2980007](https://doi.org/10.1109/tcss.2020.2980007)]
18. Huang C, Xu X, Cai Y, Ge Q, Zeng G, Li X, et al. Mining the characteristics of COVID-19 patients in China: analysis of social media posts. *J Med Internet Res* 2020 May 17;22(5):e19087 [FREE Full text] [doi: [10.2196/19087](https://doi.org/10.2196/19087)] [Medline: [32401210](https://pubmed.ncbi.nlm.nih.gov/32401210/)]
19. Chen Q, Min C, Zhang W, Wang G, Ma X, Evans R. Unpacking the black box: how to promote citizen engagement through government social media during the COVID-19 crisis. *Comput Human Behav* 2020 Sep;110:106380 [FREE Full text] [doi: [10.1016/j.chb.2020.106380](https://doi.org/10.1016/j.chb.2020.106380)] [Medline: [32292239](https://pubmed.ncbi.nlm.nih.gov/32292239/)]

20. Shen C, Chen A, Luo C, Liao W, Zhang J, Feng B. Using reports of own and others' symptoms and diagnosis on social media to predict COVID-19 case counts: observational study in mainland China. JMIR Preprints. Preprint posted online April 16, 2020. [doi: [10.2196/preprints.19421](https://doi.org/10.2196/preprints.19421)]
21. Zhao Y, Xu H. Chinese public attention to COVID-19 epidemic: based on social media. medRxiv. Preprint posted online March 20, 2020. [doi: [10.1101/2020.03.18.20038026](https://doi.org/10.1101/2020.03.18.20038026)]
22. Yin FL, Lv JH, Zhang XJ, Xia XY, Wu JH. COVID-19 information propagation dynamics in the Chinese Sina-microblog. *Math Biosci Eng* 2020 Mar 09;17(3):2676-2692 [FREE Full text] [doi: [10.3934/mbe.2020146](https://doi.org/10.3934/mbe.2020146)] [Medline: [32233560](https://pubmed.ncbi.nlm.nih.gov/32233560/)]
23. Li C, Chen LJ, Chen X, Zhang M, Pang CP, Chen H. Retrospective analysis of the possibility of predicting the COVID-19 outbreak from internet searches and social media data, China, 2020. *Euro Surveill* 2020 Mar;25(10) [FREE Full text] [doi: [10.2807/1560-7917.ES.2020.25.10.2000199](https://doi.org/10.2807/1560-7917.ES.2020.25.10.2000199)] [Medline: [32183935](https://pubmed.ncbi.nlm.nih.gov/32183935/)]
24. Li S, Wang Y, Xue J, Zhao N, Zhu T. The impact of COVID-19 epidemic declaration on psychological consequences: a study on active Weibo users. *Int J Environ Res Public Health* 2020 Mar 19;17(6) [FREE Full text] [doi: [10.3390/ijerph17062032](https://doi.org/10.3390/ijerph17062032)] [Medline: [32204411](https://pubmed.ncbi.nlm.nih.gov/32204411/)]
25. Yuan B, Liu Y, Li H. Sentiment classification in Chinese microblogs: lexicon-based and learning-based approaches. *Int Proc Economics Dev Res* 2013;68(1).
26. Mikhail B. The health belief model: a review and critical evaluation of the model, research, and practice. *Adv Nurs Sci* 1981;4(1):65-82. [doi: [10.1097/00012272-198110000-00007](https://doi.org/10.1097/00012272-198110000-00007)]
27. Rosenstock IM, Strecher VJ, Becker MH. Social learning theory and the Health Belief Model. *Health Educ Q* 1988;15(2):175-183. [doi: [10.1177/109019818801500203](https://doi.org/10.1177/109019818801500203)] [Medline: [3378902](https://pubmed.ncbi.nlm.nih.gov/3378902/)]
28. 武汉市卫生健康委员会关于不明原因的病毒性肺炎情况通报 (01-05-2020). Wuhan Municipal Health Commission. 2020. URL: <http://www.nhc.gov.cn/xcs/yqtb/202001/1beb46f061704372b7ca41ef3e682229.shtml> [accessed 2020-12-01]
29. Novel coronavirus (2019-nCoV): situation report - 1. World Health Organization. 2020 Jan 21. URL: https://www.who.int/docs/default-source/coronaviruse/situation-reports/20200121-sitrep-1-2019-ncov.pdf?sfvrsn=20a99c10_4 [accessed 2020-05-26]
30. Novel coronavirus – Thailand (ex-China). World Health Organization. 2020 Jan 14. URL: <https://www.who.int/csr/don/14-january-2020-novel-coronavirus-thailand-ex-china/en/> [accessed 2020-05-26]
31. Xiong X, Wang P, Su K, Cho WC, Xing Y. Chinese herbal medicine for coronavirus disease 2019: a systematic review and meta-analysis. *Pharmacol Res* 2020 Oct;160:105056 [FREE Full text] [doi: [10.1016/j.phrs.2020.105056](https://doi.org/10.1016/j.phrs.2020.105056)] [Medline: [32622723](https://pubmed.ncbi.nlm.nih.gov/32622723/)]
32. Li Z, Li L, Chen T, Li C, Wang D, Yang Z, et al. Efficacy and safety of Ban-Lan-Gen granules in the treatment of seasonal influenza: study protocol for a randomized controlled trial. *Trials* 2015 Mar 28;16:126 [FREE Full text] [doi: [10.1186/s13063-015-0645-x](https://doi.org/10.1186/s13063-015-0645-x)] [Medline: [25873046](https://pubmed.ncbi.nlm.nih.gov/25873046/)]
33. Pneumonia of unknown cause – China. World Health Organization. 2020 Jan 05. URL: <https://www.who.int/csr/don/05-january-2020-pneumonia-of-unkown-cause-china/en/> [accessed 2020-05-26]
34. 武汉市卫健委关于当前我市肺炎疫情的情况通报 12-31-2019. Wuhan Municipal Health Commission. 2019. URL: <http://www.nhc.gov.cn/xcs/yqtb/202001/1beb46f061704372b7ca41ef3e682229.shtml> [accessed 2020-05-26]
35. Wang Y, Moritsugu K. Human-to-human transmission confirmed in China coronavirus. Associated Press News. 2020 Jan 19. URL: <https://apnews.com/14d7dcffa205d9022fa9ea593bb2a8c5> [accessed 2020-05-26]
36. Albalawi Y, Sixsmith J. Agenda setting for health promotion: exploring an adapted model for the social media era. *JMIR Public Health Surveill* 2015;1(2):e21 [FREE Full text] [doi: [10.2196/publichealth.5014](https://doi.org/10.2196/publichealth.5014)] [Medline: [27227139](https://pubmed.ncbi.nlm.nih.gov/27227139/)]
37. Li J, Xu Q, Cuomo R, Purushothaman V, Mackey T. Data mining and content analysis of the Chinese social media platform Weibo during the early COVID-19 outbreak: retrospective observational infoveillance study. *JMIR Public Health Surveill* 2020 Apr 21;6(2):e18700 [FREE Full text] [doi: [10.2196/18700](https://doi.org/10.2196/18700)] [Medline: [32293582](https://pubmed.ncbi.nlm.nih.gov/32293582/)]

Abbreviations

- MERS:** Middle East respiratory syndrome
- SARS:** severe acute respiratory syndrome
- WHO:** World Health Organization
- 2019-nCoV:** novel coronavirus

Edited by T Sanchez; submitted 04.09.20; peer-reviewed by R Dekova, W Zhang, C Min; comments to author 09.10.20; revised version received 29.10.20; accepted 06.11.20; published 07.12.20.

Please cite as:

Xu Q, Shen Z, Shah N, Cuomo R, Cai M, Brown M, Li J, Mackey T

Characterizing Weibo Social Media Posts From Wuhan, China During the Early Stages of the COVID-19 Pandemic: Qualitative Content Analysis

JMIR Public Health Surveill 2020;6(4):e24125

URL: <http://publichealth.jmir.org/2020/4/e24125/>

doi: [10.2196/24125](https://doi.org/10.2196/24125)

PMID: [33175693](https://pubmed.ncbi.nlm.nih.gov/33175693/)

©Qing Xu, Ziyi Shen, Neal Shah, Raphael Cuomo, Mingxiang Cai, Matthew Brown, Jiawei Li, Tim Mackey. Originally published in JMIR Public Health and Surveillance (<http://publichealth.jmir.org>), 07.12.2020. This is an open-access article distributed under the terms of the Creative Commons Attribution License (<https://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in JMIR Public Health and Surveillance, is properly cited. The complete bibliographic information, a link to the original publication on <http://publichealth.jmir.org>, as well as this copyright and license information must be included.

Original Paper

Associations of Medications With Lower Odds of Typical COVID-19 Symptoms: Cross-Sectional Symptom Surveillance Study

Dietmar Urbach^{1,2}, MD, Prof Dr; Friedemann Awiszus², MSc, MD, Prof Dr; Sven Leiß³, MSc; Tamsin Venton⁴, MBBS, MRCP, MChEd; Alexander Vincent De Specht⁵; Christian Apfelbacher⁶, Prof Dr, PhD

¹Helios-Klinikum Gifhorn, Gifhorn, Germany

²Department of Orthopaedic Surgery, Otto von Guericke University, Magdeburg, Germany

³Gutingi-Medical Outpatient Clinic, Göttingen, Germany

⁴Teign Estuary Medical Group, Teignmouth, United Kingdom

⁵University of Potsdam, Potsdam, Germany

⁶Institute of Social Medicine and Health Systems Research, Otto von Guericke University, Magdeburg, Germany

Corresponding Author:

Dietmar Urbach, MD, Prof Dr

Department of Orthopaedic Surgery

Otto von Guericke University

Leipziger Str. 44

39122

Magdeburg, 39122

Germany

Phone: 49 537187 ext 3353

Email: dietmar.urbach@med.ovgu.de

Abstract

Background: As the COVID-19 pandemic continues to spread across the globe, the search for an effective medication to treat the symptoms of COVID-19 continues as well. It would be desirable to identify a medication that is already in use for another condition and whose side effect profile and safety data are already known and approved.

Objective: The objective of this study was to evaluate the effect of different medications on typical COVID-19 symptoms by using data from an online surveillance survey.

Methods: Between early April and late-July 2020, a total of 3654 individuals in Lower Saxony, Germany, participated in an online symptom-tracking survey conducted through the app covid-nein-danke.de. The questionnaire comprised items on typical COVID-19 symptoms, age range, gender, employment in patient-facing healthcare, housing status, postal code, previous illnesses, permanent medication, vaccination status, results of reverse transcription polymerase chain reaction (RT-PCR) and antibody tests for COVID-19 diagnosis, and consequent COVID-19 treatment if applicable. Odds ratio estimates with corresponding 95% CIs were computed for each medication and symptom by using logistic regression models.

Results: Data analysis suggested a statistically significant inverse relationship between typical COVID-19 symptoms self-reported by the participants and self-reported statin therapy and, to a lesser extent, antihypertensive therapy. When COVID-19 diagnosis was based on restrictive symptom criteria (ie, presence of 4 out of 7 symptoms) or a positive RT-PCR test, a statistically significant association was found solely for statins (odds ratio 0.28, 95% CI 0.1-0.78).

Conclusions: Individuals taking statin medication are more likely to have asymptomatic COVID-19, in which case they may be at an increased risk of transmitting the disease unknowingly. We suggest that the results of this study be incorporated into symptoms-based surveillance and decision-making protocols in regard to COVID-19 management. Whether statin therapy has a beneficial effect in combating COVID-19 cannot be deduced based on our findings and should be investigated by further study.

Trial Registration: German Clinical Trials Register DRKS00022185; https://www.drks.de/drks_web/navigate.do?navigationId=trial.HTML&TRIAL_ID=DRKS00022185; World Health Organization International Clinical Trials Registry Platform U1111-1252-6946

(*JMIR Public Health Surveill* 2020;6(4):e22521) doi:[10.2196/22521](https://doi.org/10.2196/22521)

KEYWORDS

COVID-19; SARS-CoV-2; statins; antihypertensives; surveillance; hydroxymethyl-glutaryl-coenzyme A reductase inhibitors; online survey

Introduction

More than 11 months have passed since SARS-CoV-2 infection was first detected in Wuhan, China, but the worldwide incidence of COVID-19 is still increasing [1]. Despite widespread research efforts, no curative therapies for COVID-19 have been established, and a safe vaccine is unlikely to become available before 2021. In Germany, the first known case of infection with SARS-CoV-2 was reported in the end of January 2020, and a peak of new infections was noted during March and April [2,3].

Early epidemiological studies of the disease demonstrated that age and preexisting medical conditions, in particular cardiopulmonary diseases, are associated with a high mortality rate in patients hospitalized due to COVID-19 [4]. However, it remains unclear why some individuals within high-risk groups have severe disease, whereas others do not. Moreover, the role of medication, as well as vaccination status, in preventing patients with COVID-19 from becoming severely ill remains debated [5,6]. With regard to the use of statins (also known as hydroxymethylglutaryl-coenzyme A reductase inhibitors) in particular, 3 recent studies found these medications have a direct effect on COVID-19 severity and outcomes [7-9].

In addition, there was insufficient surveillance of the disease when the infection spread to Germany. COVID-19 surveillance testing based on reverse transcription polymerase chain reaction (RT-PCR) results was initiated by Robert Koch Institution (RKI) in Germany. However, due to limited testing resources, only a small cohort of people were included during the first wave of COVID-19. Furthermore, no surveillance system based on typical COVID-19 symptoms had been established in Germany at that time.

Many management decisions and recommendations regarding COVID-19 are based on the presence of typical symptoms. These include screening for patients with suspected COVID-19, an indication algorithm for PCR testing, and recommendations for self-isolation. In addition, symptom tracking at the regional level has been used to identify increases in infection rate [10,11]. At the beginning of this study, the following symptoms were commonly observed in patients with laboratory-confirmed COVID-19: fever, dyspnea, dry cough, sore throat, myalgia, headache, ageusia, and anosmia [4,12].

Therefore, to address the abovementioned research challenges and test a symptom-based regional surveillance system, we decided to combine an online symptom-tracking app with the elicitation of medical data that might have an impact on COVID-19 cases. The survey was rolled out at the end of March 2020 as a pilot project in Lower Saxony, Germany. At the same time, a symptom-tracking app was distributed in the UK [10]. Later, symptom trackers were established successfully in more regions [13].

Thus, the aim of this study was to evaluate the effects of different medications on typical COVID-19 symptoms by using data from our surveillance survey.

Methods

Study Recruitment

For the pilot study, we recruited participants from the administrative district of Gifhorn in the German federal state of Lower Saxony, by advertising via regional newspaper articles, a YouTube video, social media, and regional broadcasts.

Data Collection

Data were collected using an online questionnaire implemented by the browser-based app “covid-nein-danke.de” [14], which was developed between March 10 and 27, 2020, by 2 authors (SL and DU). For this evaluation, we considered data entered by participants from April 2 to July 20, 2020.

The questionnaires were completed using a computer or an internet-enabled mobile phone or tablet device. Owing to data protection requirements, the app was developed as a browser-based app that did not require users to download a program. Technically, the study was based on a single-page app written in JavaScript and a highly scalable cloud. To address the estimated high data volumes and make the questionnaire adaptable for changes, a NoSQL (non-structured query language) database was used.

The survey was described and initiated under the URL covid-nein-danke.de [14]. The overall time taken to complete the survey was approximately 3-5 minutes. After finishing the survey, a 7-digit code was randomly generated and provided to the user for follow-up surveys. The app worked without user “tracking”—neither their email address nor IP address was stored. Users were not identified in any way; thus, data collection was completely anonymous.

Questionnaire Items

The questionnaire contained items on age range, gender (male, female, and nonbinary for those reporting their gender as diverse), employment in patient-facing health care, housing status, postal code, previous illnesses, permanent medication, vaccination status, and symptoms. It also included the results of any COVID-19 PCR or antibody tests and any COVID-19 treatment received. More specifically, the following new COVID-19 symptoms were assessed: dry cough, increased body temperature or fever (>37.5°C), shortness of breath, muscle or joint pain, sore throat, headache, and loss of smell or taste. The participants confirmed “yes” or “no” for each question.

For the question “Do you take regular medication?” if the participant responded “yes,” a list of medications was displayed for the participant to select by using a “yes-no” slider. Medications listed included cholesterol-lowering medication (eg, simvastatin), nonsteroid anti-inflammatory drugs (NSAIDs, such as ibuprofen and diclofenac), thyroid medication (eg,

levothyroxine), omeprazole/pantoprazole, metamizole, antihypertensives, furosemide or hydrochlorothiazide (HCT), cortisone, disease-modifying antirheumatic drugs (DMARDs, eg, methotrexate, biologics, hydroxychloroquine, and antihistamines). If “antihypertensives” were chosen, participants were asked to choose from the following selection: ramipril, beta-blockers metoprolol, bisoprolol, and amlodipine. Participants could also provide further information on medications not explicitly requested in a free-text field.

Statistical Analysis

The raw data were transformed from a JavaScript Object Notation format to a rational data format for further evaluation. Data were analyzed using SAS/STAT software (SAS Institute Inc.). To investigate associations between typical COVID-19 symptoms and medical characteristics, we ran logistic regression models (logit model). Odds ratio (OR) estimates with corresponding 95% CIs were computed for each medication and symptom. Based on the assumption that the presence of 4 out of 7 typical symptoms indicates COVID-19, the association of COVID-19 with concomitant medication intake was similarly determined.

Ethics and Informed Consent

The online study was approved by the ethics committee of the Otto-von-Guericke-University Magdeburg (Ref. 65-20). This study is registered with the German Clinical Trial Register (No. DRKS00022185) and World Health Organization (WHO)

International Clinical Trials Registry Platform U1111-1252-6946.

An overview of the aims of this survey is provided on the homepage of the app’s website [14]. Furthermore, a link directs participants to the details of the survey and data evaluation. Before the questionnaire could be opened, participants were required to agree to the data privacy policy according to European General Data Protection Regulation. Another page informed the participants about data storage, processing, and evaluation. They were also informed about their rights and that participation was not associated with any direct benefit or compensation. Furthermore, the participants were required to confirm that they were over 18 years old before proceeding to the questionnaire.

Results

Epidemiological Data

From April 2 to July 20, a total of 3990 people participated in the online survey. From these, data from 3654 participants were further evaluated. Data from the remaining 336 participants were excluded owing to incomplete symptom data entry. The peak age ranges were 50-59 years for female participants and 60-69 years for male participants. Overall, there were more female participants (2250/3654, 61.6%) than male participants (1394/3654, 38.1%; Table 1).

Table 1. Gender-specific age-range distribution for participants of the online survey conducted between April and July 2020.

Age range, years	Gender, n (%)			
	Male	Female	Nonbinary	Not stated
18-29	97 (7.0)	235 (10.4)	1 (33.3)	N/A ^a
30-39	154 (11.0)	359 (16.0)	N/A	1 (14.3)
40-49	234 (16.8)	471 (20.9)	N/A	N/A
50-59	339 (24.3)	619 (27.5)	1 (33.3)	3 (42.9)
60-69	342 (24.5)	422 (18.8)	1 (33.3)	2 (28.6)
70-79	186 (13.3)	117 (5.2)	0 (0.0)	1 (14.3)
80-89	42 (3.0)	25 (1.1)	0 (0.0)	0 (0.0)
>90	0 (0.0)	2 (0.1)	N/A	N/A

^aN/A: not applicable.

Of the 3654 respondents, 99 were tested by RT-PCR at the same time as they participated in the survey. Of these, 16.16% (16/99) participants tested positive for SARS-CoV-2, corresponding to only 0.44% (16/3654) of all survey participants.

Medications

We found significantly lower odds of self-reported symptoms for COVID-19 among participants taking statin,

antihypertensive, and diuretic medications. In contrast, significantly higher odds of self-reported COVID-19 symptoms was associated with participants taking DMARDs, metamizole, and cortisone. Results of the logistic regression analysis for specific medications are presented in Table 2. The findings show a significant association between certain medications and either higher or lower self-reported odds of COVID-19 symptoms.

Table 2. Strength of association between medication and odds of typical COVID-19 symptoms that were self-reported (N=3645).

Medication	Number of participants taking medication, n (%)	COVID-19 symptom, odds ratio estimate (CI ^a)						
		Headache	Fever	Loss of smell or taste	Sore throat	Shortness of breath	Joint-muscle pain	Dry cough
Statins	358 (10)	<i>0.42</i> (0.28-0.64) ^b	0.43 (0.13-1.45)	0.67 (0.29-1.53)	<i>0.54</i> (0.35-0.85)	1.15 (0.71-1.87)	0.87 (0.56-1.34)	<i>0.61</i> (0.43-0.88)
NSAIDs ^c	212 (6)	<i>1.93</i> (1.38-2.7)	0.4 (0.09-1.67)	0.91 (0.36-2.34)	<i>1.58</i> (1.08-2.31)	<i>2.36</i> (1.48-3.75)	<i>2.1</i> (1.41-3.13)	<i>1.57</i> (1.10-2.23)
Thyroid medication	585 (16)	1.13 (0.89-1.43)	0.63 (0.30-1.32)	0.62 (0.33-1.19)	0.78 (0.59-1.04)	0.84 (0.56-1.26)	1.02 (0.75-1.39)	0.93 (0.72-1.20)
Omeprazole/ pantoprazole	399 (11)	0.95 (0.70-1.3)	1.62 (0.77-3.42)	0.71 (0.33-1.52)	1.15 (0.83-1.61)	0.93 (0.58-1.47)	1.07 (0.74-1.56)	0.81 (0.59-1.12)
Metamizole	127 (3)	<i>2.31</i> (1.50-3.55)	1.47 (0.47-4.56)	<i>2.91</i> (1.17-7.22)	1.44 (0.87-2.40)	<i>2.62</i> (1.45-4.73)	<i>2.44</i> (1.47-4.05)	<i>1.74</i> (1.10-2.74)
Antihypertensives (all)	1094 (30)	0.76 (0.55-1.04)	0.48 (0.18-1.26)	1.18 (0.59-2.36)	<i>0.65</i> (0.45-0.93)	1.44 (0.92-2.26)	0.96 (0.65-1.42)	1.22 (0.90-1.65)
Furosemide or hydrochlorothiazide	192 (5)	0.71 (0.44-1.15)	0.58 (0.13-2.64)	0.92 (0.35-2.41)	<i>0.39</i> (0.20-0.75)	0.59 (0.29-1.21)	0.71 (0.40-1.27)	1.02 (0.67-1.57)
Cortisone	169 (5)	1.24 (0.83-1.86)	1.47 (0.54-3.98)	0.96 (0.33-2.79)	1.26 (0.81-1.97)	<i>1.83</i> (1.05-3.18)	<i>1.8</i> (1.12-2.90)	1.26 (0.82-1.92)
DMARDs ^d	56 (2)	0.5 (0.23-1.09)	0.66 (0.08-5.30)	0.82 (0.11-6.33)	1.66 (0.85-3.23)	1.6 (0.69-3.76)	0.54 (0.20-1.45)	1.01 (0.49-2.05)
Antihistamines	239 (7)	1.31 (0.94-1.82)	0.73 (0.26-2.07)	0.98 (0.42-2.32)	1.12 (0.77-1.65)	1.22 (0.72-2.05)	0.91 (0.57-1.45)	0.97 (0.67-1.41)
Biologics	142 (4)	<i>1.75</i> (1.18-2.59)	1.32 (0.46-3.79)	0.24 (0.03-1.79)	0.85 (0.51-1.43)	0.57 (0.25-1.28)	0.92 (0.52-1.63)	0.95 (0.59-1.52)
Hydroxy-chloroquine	28 (1)	1.8 (0.76-4.25)	1.72 (0.22-13.8)	— ^e	1.66 (0.66-4.16)	0.97 (0.26-3.54)	0.49 (0.11-2.15)	1.44 (0.59-3.54)
Subgroup ARBs ^f	39 (1)	0.87 (0.33-2.34)	—	—	0.52 (0.12-2.21)	1.21 (0.35-4.14)	0.9 (0.26-3.05)	1.14 (0.48-2.67)
Subgroup ACEIs ^g (eg, ramipril)	412 (11)	0.94 (0.65-1.37)	0.93 (0.31-2.83)	<i>0.38</i> (0.15-0.93)	1.16 (0.76-1.75)	0.85 (0.50-1.44)	1.12 (0.72-1.74)	0.93 (0.66-1.31)
Subgroup beta-blockers	437 (12)	0.95 (0.65-1.37)	1.9 (0.66-5.46)	2.1 (1.01-4.35)	1.24 (0.82-1.87)	0.82 (0.49-1.39)	1.05 (0.68-1.64)	1.14 (0.81-1.59)
Subgroup calcium-channel blockers (eg, amlodipine)	209 (6)	1.35 (0.88-2.06)	1.14 (0.31-4.16)	1.49 (0.65-3.39)	1.23 (0.75-2.00)	0.74 (0.38-1.46)	0.66 (0.36-1.19)	1.06 (0.70-1.59)

^aLower and upper limits of 95% Wald confidence interval.^bItalic text indicates statistically significant values.^cNSAIDs: nonsteroidal anti-inflammatory drugs.^dDMARDs: disease-modifying antirheumatic drugs.^eNot applicable (ie, numbers were too low to be calculated).^fARBs: angiotensin receptor blocker.^gACEIs: angiotensin converting enzyme inhibitors.

Statins

Of the 3654 participants, 358 (9.8%) indicated that they were taking regular statin medications. The regular intake of statin medication was significantly associated with lower odds of those participants reporting symptoms such as sore throat, dry cough, and headache. The odds of loss of smell or taste, as well as fever, were also decreased among these participants; however,

it did not reach statistical significance. No association was found between statin medication and the odds of shortness of breath and joint or muscle pain. Statistically significant associations were found for both male and female participants with respect to headache, and only for female participants with respect to sore throat despite a lowered statistical power through gender stratification (Table 3).

Table 3. Gender-stratified strength of association between statin administration and typical COVID-19 symptoms (n=358). Nonbinary participants (n=3) and those not reporting their gender (n=7) were not included in the analysis due to low numbers.

Gender (n)	COVID-19 symptom, odds ratio estimate (95% CI ^a)						
	Headache	Fever	Loss of smell or taste	Sore throat	Shortness of breath	Joint or muscle pain	Dry cough
Female (2250)	<i>0.3</i> ^b (0.15-0.59)	0.63 (0.15-2.61)	0.85 (0.26-2.76)	<i>0.27</i> (0.12-0.61)	1.28 (0.63-2.57)	0.77 (0.38-1.53)	0.84 (0.5-1.42)
Male (1394)	0.58 (0.35-0.95)	0.21 (0.03-1.58)	0.68 (0.24-1.95)	0.73 (0.44-1.2)	1.23 (0.67-2.25)	0.97 (0.59-1.6)	0.65 (0.41-1.02)

^aLower and upper limits of 95% Wald confidence interval.

^bItalic text indicates statistically significant values.

Antihypertensives

Of the 3654 participants, 1094 (29.9%) indicated that they were taking regular antihypertensive medication. These participants had significantly lower odds of reporting sore throat. The odds of reporting symptoms such as fever and headache were also decreased in this group, but these associations did not reach statistical significance. Participants taking angiotensin converting enzyme inhibitors (ACEIs) were found to have significantly lower odds of reporting loss of smell or taste.

Furosemide or HCT

In all, 192 of 3654 (5.3%) participants were taking diuretics (ie, either furosemide or HCT). Diuretic intake was significantly associated with lower odds of these participants reporting sore throat.

NSAID and Metamizole

NSAID medication was taken by 212 (5.8%) participants and metamizole, by 127 (3.5%) of all 3654 participants. Participants

using NSAIDs had significantly higher odds of reporting typical COVID-19 symptoms such as headache, sore throat, shortness of breath, joint or muscle pain, and dry cough. In contrast, metamizole use was associated with lower odds of reported headache, loss of smell or taste, shortness of breath, joint or muscle pain, and dry cough. The numbers and corresponding percentages of symptoms observed for each medication used for COVID-19 symptom treatment are shown in Table S1 in Multimedia Appendix 1.

By making a presumptive diagnosis of COVID-19, either by a positive RT-PCR test or based on the presence of 4 out of 7 positive symptoms, we were able to detect 142 cases of infections among the 3654 participants. Furthermore, statistical analyses revealed a marked inverse association between COVID-19 cases and statin use with an OR of 0.28 (95% CI 0.1-0.78). All other medications did not show a statistically significant association (Table 4).

Table 4. Strength of association between statins and presumed COVID-19 diagnosis based on a positive reverse transcription polymerase chain reaction test (n=16) or presence of symptoms (minimum 4 out of 7 typical symptoms, n=126).

Medication	Odds ratio estimates (95% CI ^a)
Statins	<i>0.28</i> ^b (0.10-0.78)
NSAIDs ^c (eg, diclofenac, ibuprofen)	1.75 (0.93-3.27)
Thyroid medication	1.01 (0.64-1.62)
Omeprazole/ pantoprazole	1.10 (0.61-2.00)
Metamizole	1.75 (0.77-3.97)
Antihypertensives (all)	0.63 (0.32-1.24)
Furosemide or hydrochlorothiazide	0.24 (0.06-1.03)
Cortisone	1.83 (0.91-3.66)
DMARDs ^d	0.90 (0.25-3.23)
Antihistamines	1.10 (0.58-2.08)
Biologics	0.30 (0.07-1.24)
Hydrochloroquine	1.33 (0.28-6.24)
Subgroup ARBs ^e sartane	1.19 (0.15-9.25)
Subgroup ACEIs ^f (eg, ramipril)	1.17 (0.55-2.47)
Subgroup beta-blockers	0.90 (0.25-3.23)
Subgroup calcium-channel blockers (eg, amlodipine)	1.10 (0.58-2.08)

^aLower and upper 95% Wald confidence intervals.

^bItalic text indicates statistically significant values.

^cNSAIDs: nonsteroidal anti-inflammatory drugs.

^dDMARDs: disease-modifying antirheumatic drugs.

^eARBs: angiotensin receptor blocker.

^fACEIs: angiotensin converting enzyme inhibitors.

Discussion

Principal Findings

The main finding of our study is a statistically significant inverse relationship between self-reported symptoms typical for COVID-19 and statin therapy and, to a lesser extent, antihypertensive therapy. As the world continues to search for a medication to cure or attenuate COVID-19, it would be desirable, and fortuitous, to identify such a medication that is already in use for another condition and whose side effect profile and safety data are already known and approved. In the search for such medication, we combined a COVID-19 symptom surveillance survey with a prospective observational study in which participants' medication intake was assessed.

COVID-19 was assumed based on a positive RT-PCR test, hospital admission, professional treatment, or presence of a minimum of 4 out of 7 typical symptoms. Fortunately, the incidence of confirmed COVID-19 cases was low in the study area (Lower Saxony, Germany). During the study period, RKI recorded 208 cases based on positive RT-PCR tests and 4 deaths due to COVID-19 in this region [2]. Nevertheless, the statistical evaluation of the data demonstrated significant results regarding typical COVID-19 symptoms and medication intake.

Our prospective surveillance survey asked participants to indicate any presence of symptoms, dry cough, sore throat, fever, joint or muscle pain, shortness of breath, loss of smell or taste, and headache, only if they were new occurrences. On the initiation of the survey at the beginning of March, gastrointestinal symptoms were considered an uncommon symptom for COVID-19 [4]. Therefore, we did not include gastrointestinal symptoms such as abdominal cramping or diarrhea in our analysis. These symptoms, however, have been incorporated into the questionnaire of the ongoing survey. Of all the participant characteristics collected, we statistically evaluated the role of gender in detail because age and gender play an important role in the mortality and severity of COVID-19 [15]. Further stratification based on other characteristics would have led to small subcohorts hampering meaningful statistical analyses.

A Cochrane review [12] found 6 symptoms in at least one study with a sensitivity of more than 50%; these included cough, sore throat, fever, myalgia or arthralgia, fatigue, and headache. Of these symptoms, fever, joint or muscle pain, fatigue, and headache were considered red flags as their specificity was greater than 90%, resulting in a positive likelihood ratio of at least 5 for COVID-19 [12]. It was hypothesized that a combination of symptoms could lead to an increase in sensitivity

and specificity. However, they found no study that had assessed combinations of different symptoms. As we were unable to use an evidence base to weigh the sensitivity and specificity of individual symptoms, we selected 4 out of the 7 symptoms to define symptomatic COVID-19.

We found that taking medication such as NSAIDs as well as metamizole was significantly associated with higher odds for most COVID-19 symptoms evaluated. This is an unsurprising finding given that NSAIDs and metamizole are typical medications for treating such symptoms. Moreover, cortisone was associated with a significantly higher self-reported odds of dry cough. It can be postulated that patients with chronic obstructive pulmonary disease take cortisone more frequently and present with this symptom more often. Intake of biologics was found to be significantly associated with higher odds of headache. Headache is a known side effect of these medications, which may explain these statistical results. Nevertheless, these findings are important as positive indicators to the reliability of the data reported by the participants.

Of the medications associated with lower odds of self-reported typical COVID-19 symptoms, statins showed the most distinct results. Most common symptoms reported by participants using statins were dry cough, sore throat, and headache. In addition, statins were associated with lower odds of fever, joint or muscle pain, and loss of smell or taste. However, the latter associations did not reach statistical significance.

When we defined a COVID-19 diagnosis based on the presence of 4 of 7 symptoms or a positive RT-PCR test, the result was more obvious with an OR of 0.28 (95% CI 0.1-0.78). However, we did not find such significant associations between COVID-19 symptoms and other evaluated medications.

Based on our findings, we suggest 2 most likely explanations for the observed association between statin use and the lower odds of symptoms suggestive of COVID-19. First, statin therapy may either prevent SARS-CoV-2 infection or lower the symptom burden of COVID-19. This hypothesis is in line with 3 recent clinical studies. In a retrospective study of 154 nursing home residents with COVID-19, statin therapy was significantly associated with the absence of symptoms [8]. The researchers defined COVID-19 by either a positive PCR test or the presence of typical COVID-19 symptoms. Two other studies support the direct influence of statin use on COVID-19; they found a significantly lower disease severity among hospitalized patients with COVID-19 [9] and lower mortality among those who received concomitant statin medication [7]. At first sight, it seems implausible that taking statin medication could prevent a SARS-CoV-2 infection. However, a direct protective effect of statins against SARS-CoV-2 infection was recently proposed by Reiner et al [16], using a molecular docking study. From our results so far, it would be premature to assess whether statins have a preventative effect. We hope that our prospective study will shed further light on this potential use of statins when more participants undergo PCR testing.

The second possible explanation for our finding is that the encountered symptoms are independent of COVID-19. The evaluated symptoms are recognized as typical for COVID-19, but they also overlap with other illnesses such as allergies,

non-COVID-19 flu-like viral infections, or migraine. Statins might act on those symptoms independently of COVID-19. In this context, it was shown that statins in combination with vitamin D can reduce migraine [17]. Furthermore, the results of previous studies point to the fact that statins are an option for treating the symptoms of influenza [18,19] and pneumonia [20-22]. In summary, it is already accepted that statins have pleiotropic, anti-inflammatory, and immunomodulatory effects [23], which would explain our findings. It is also possible that a combination of both explanations, that is, an anti-inflammatory effect on both COVID-19 and non-COVID-19 illness, could explain the finding of significant associations between statins and lower self-reported odds of typical COVID-19 symptoms.

Our study findings also suggest that antihypertensives were associated with a significantly lower self-reported odds of dry cough. A similar trend in decreased self-reporting of fever and headache was also observed. Statistical analyses of the subgroups ARBs, ACEIs, beta-blockers, and calcium-channel antagonists led to insignificant results except for an association between ACEIs and loss of smell or taste (OR 0.38, 95% CI 0.15-0.93). This finding might be of interest, as loss of smell and taste have recently been proposed as cardinal symptoms for COVID-19 [13]. As the subgroups were very small, the latter results must be interpreted with caution. The intake of antidiuretics, furosemide and HCT, was associated with lower odds of sore throat but no reduction in the other symptoms. We have no explanation for this association, neither from our data nor from the literature.

Regardless of whether statins and antihypertensives act on symptoms linked to COVID-19, or whether they act on symptoms independent of COVID-19, we must keep in mind that those symptoms might be masked by this medication. Surveillance recommendations and medical assessments based on typical symptoms may not be reliable in patients taking statins and antihypertensives. Furthermore, individuals receiving statin therapy may be more likely to have asymptomatic infection and therefore at a greater risk of transmitting the infection unknowingly.

Our results should not be interpreted as a recommendation to take statins or hypertensive drugs for prevention of COVID-19 or to reduce disease severity. We are mindful of the fact that large studies have shown no positive effect of statins in intensive care patients and in sepsis-associated acute respiratory distress syndrome [24,25]. Furthermore, a large study has been discontinued because of the lack of benefit and evidence of significant early renal and liver failure while taking rosuvastatin medication [26]. Nevertheless, our data support the hypothesis that statins and antihypertensives may play a role in COVID-19 treatment and emphasize the potential value of ongoing clinical studies (eg, NCT04348695, NCT04343001, and NCT04351581).

Study Limitations

Because of the nature of the survey, there are a few limitations to the study. First, the results are based on a self-selected group who are not necessarily representative of the general population. Second, self-assessment of symptoms is purely subjective. Nevertheless, we found plausible data from the NSAID, metamizole, and cortisone medication groups, which indicated

that the participants completed symptom reporting seriously. Although very unlikely, we cannot rule out, that participants repeated the survey more than once because of its anonymous nature.

Conclusions

The exact association between statin medications and the outcome of reduced symptoms in the study population is uncertain. It is possible that statins have a therapeutic or preventive effect on COVID-19; it is equally possible that uninfected individuals receiving these drugs have a lower

prevalence of symptoms unrelated to COVID-19. Thus, future studies are needed to evaluate the potential benefits of statins in patients with COVID-19.

Furthermore, we propose that statin therapy masks or reduces the symptoms in patients with SARS-CoV-2 infection. As such, patients receiving statin therapy may be more likely to have asymptomatic COVID-19, in which case they are at an increased risk of transmitting it unknowingly. We suggest that our study results are incorporated in the symptoms-based surveillance and decision-making protocols for COVID-19 management.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Symptoms observed for different medications used for COVID-19 treatment.

[DOCX File, 30 KB - [publichealth_v6i4e22521_app1.docx](#)]

References

1. WHO Coronavirus Disease (COVID-19) Dashboard. World Health Organization. URL: <https://covid19.who.int> [accessed 2020-07-19]
2. Robert-Koch-Institut. Erfassung der SARS-CoV-2-Testzahlen in Deutschland (Update vom 15.4.2020). *Epid Bull* 2020 Apr 16;16:10. [doi: [10.25646/6756.3](https://doi.org/10.25646/6756.3)]
3. Böhmer MM, Buchholz U, Corman VM, Hoch M, Katz K, Marosevic DV, et al. Investigation of a COVID-19 outbreak in Germany resulting from a single travel-associated primary case: a case series. *Lancet Infect Dis* 2020 Aug;20(8):920-928 [FREE Full text] [doi: [10.1016/S1473-3099\(20\)30314-5](https://doi.org/10.1016/S1473-3099(20)30314-5)] [Medline: [32422201](https://pubmed.ncbi.nlm.nih.gov/32422201/)]
4. Huang C, Wang Y, Li X, Ren L, Zhao J, Hu Y, et al. Clinical features of patients infected with 2019 novel coronavirus in Wuhan, China. *Lancet* 2020 Feb 15;395(10223):497-506 [FREE Full text] [doi: [10.1016/S0140-6736\(20\)30183-5](https://doi.org/10.1016/S0140-6736(20)30183-5)] [Medline: [31986264](https://pubmed.ncbi.nlm.nih.gov/31986264/)]
5. Covián C, Retamal-Díaz A, Bueno SM, Kalergis AM. Could BCG vaccination induce protective trained immunity for SARS-CoV-2? *Front Immunol* 2020;11:970 [FREE Full text] [doi: [10.3389/fimmu.2020.00970](https://doi.org/10.3389/fimmu.2020.00970)] [Medline: [32574258](https://pubmed.ncbi.nlm.nih.gov/32574258/)]
6. Sharma A, Kumar Sharma S, Shi Y, Bucci E, Carafoli E, Melino G, et al. BCG vaccination policy and preventive chloroquine usage: do they have an impact on COVID-19 pandemic? *Cell Death Dis* 2020 Jul 08;11(7):516 [FREE Full text] [doi: [10.1038/s41419-020-2720-9](https://doi.org/10.1038/s41419-020-2720-9)] [Medline: [32641762](https://pubmed.ncbi.nlm.nih.gov/32641762/)]
7. Zhang X, Qin J, Cheng X, Shen L, Zhao Y, Yuan Y, et al. In-hospital use of statins is associated with a reduced risk of mortality among individuals with COVID-19. *Cell Metab* 2020 Aug 04;32(2):176-187.e4 [FREE Full text] [doi: [10.1016/j.cmet.2020.06.015](https://doi.org/10.1016/j.cmet.2020.06.015)] [Medline: [32592657](https://pubmed.ncbi.nlm.nih.gov/32592657/)]
8. De Spiegeleer A, Bronselaer A, Teo JT, Byttebier G, De Tré G, Belmans L, et al. The effects of ARBs, ACEis, and statins on clinical outcomes of COVID-19 infection among nursing home residents. *J Am Med Dir Assoc* 2020 Jul;21(7):909-914.e2 [FREE Full text] [doi: [10.1016/j.jamda.2020.06.018](https://doi.org/10.1016/j.jamda.2020.06.018)] [Medline: [32674818](https://pubmed.ncbi.nlm.nih.gov/32674818/)]
9. Tan WYT, Young BE, Lye DC, Chew DEK, Dalan R. Statin use is associated with lower disease severity in COVID-19 infection. *Sci Rep* 2020 Oct 15;10(1):17458 [FREE Full text] [doi: [10.1038/s41598-020-74492-0](https://doi.org/10.1038/s41598-020-74492-0)] [Medline: [33060704](https://pubmed.ncbi.nlm.nih.gov/33060704/)]
10. Menni C, Valdes AM, Freidin MB, Sudre CH, Nguyen LH, Drew DA, et al. Real-time tracking of self-reported symptoms to predict potential COVID-19. *Nat Med* 2020 Jul;26(7):1037-1040. [doi: [10.1038/s41591-020-0916-2](https://doi.org/10.1038/s41591-020-0916-2)] [Medline: [32393804](https://pubmed.ncbi.nlm.nih.gov/32393804/)]
11. Echeverría P, Mas Bergas MA, Puig J, Isnard M, Massot M, Vedia C, et al. COVIDApp as an innovative strategy for the management and follow-up of COVID-19 cases in long-term care facilities in Catalonia: implementation study. *JMIR Public Health Surveill* 2020 Jul 17;6(3):e21163 [FREE Full text] [doi: [10.2196/21163](https://doi.org/10.2196/21163)] [Medline: [32629425](https://pubmed.ncbi.nlm.nih.gov/32629425/)]
12. Struyf T, Deeks J, Dinnes J, Takwoingi Y, Davenport C, Leeflang MM, Cochrane COVID-19 Diagnostic Test Accuracy Group. Signs and symptoms to determine if a patient presenting in primary care or hospital outpatient settings has COVID-19 disease. *Cochrane Database Syst Rev* 2020 Jul 07;7:CD013665 [FREE Full text] [doi: [10.1002/14651858.CD013665](https://doi.org/10.1002/14651858.CD013665)] [Medline: [32633856](https://pubmed.ncbi.nlm.nih.gov/32633856/)]
13. Zens M, Brammertz A, Herpich J, Südkamp N, Hinterseer M. App-based tracking of self-reported COVID-19 symptoms: analysis of questionnaire data. *J Med Internet Res* 2020 Sep 09;22(9):e21956 [FREE Full text] [doi: [10.2196/21956](https://doi.org/10.2196/21956)] [Medline: [32791493](https://pubmed.ncbi.nlm.nih.gov/32791493/)]
14. COVID-Nein-Danke-App Overview [In German]. 2020. URL: <https://www.covid-nein-danke.de/> [accessed 2020-12-09]

15. Bhopal SS, Bhopal R. Sex differential in COVID-19 mortality varies markedly by age. *Lancet* 2020 Aug 22;396(10250):532-533 [[FREE Full text](#)] [doi: [10.1016/S0140-6736\(20\)31748-7](https://doi.org/10.1016/S0140-6736(20)31748-7)] [Medline: [32798449](#)]
16. Reiner Ž, Hatamipour M, Banach M, Pirro M, Al-Rasadi K, Jamialahmadi T, et al. Statins and the COVID-19 main protease: evidence on direct interaction. *Arch Med Sci* 2020;16(3):490-496 [[FREE Full text](#)] [doi: [10.5114/aoms.2020.94655](https://doi.org/10.5114/aoms.2020.94655)] [Medline: [32399094](#)]
17. Buettner C, Nir R, Bertisch SM, Bernstein C, Schain A, Mittleman MA, et al. Simvastatin and vitamin D for migraine prevention: A randomized, controlled trial. *Ann Neurol* 2015 Dec;78(6):970-981 [[FREE Full text](#)] [doi: [10.1002/ana.24534](https://doi.org/10.1002/ana.24534)] [Medline: [26418341](#)]
18. Fedson DS. Treating influenza with statins and other immunomodulatory agents. *Antiviral Res* 2013 Sep;99(3):417-435. [doi: [10.1016/j.antiviral.2013.06.018](https://doi.org/10.1016/j.antiviral.2013.06.018)] [Medline: [23831494](#)]
19. Fedson DS. Clinician-initiated research on treating the host response to pandemic influenza. *Hum Vaccin Immunother* 2018 Mar 04;14(3):790-795 [[FREE Full text](#)] [doi: [10.1080/21645515.2017.1378292](https://doi.org/10.1080/21645515.2017.1378292)] [Medline: [29058516](#)]
20. Sapey E, Patel JM, Greenwood H, Walton GM, Grudzinska F, Parekh D, et al. Simvastatin improves neutrophil function and clinical outcomes in pneumonia. A pilot randomized controlled clinical trial. *Am J Respir Crit Care Med* 2019 Nov 15;200(10):1282-1293 [[FREE Full text](#)] [doi: [10.1164/rccm.201812-2328OC](https://doi.org/10.1164/rccm.201812-2328OC)] [Medline: [31206313](#)]
21. Mortensen EM, Nakashima B, Cornell J, Copeland LA, Pugh MJ, Anzueto A, et al. Population-based study of statins, angiotensin II receptor blockers, and angiotensin-converting enzyme inhibitors on pneumonia-related outcomes. *Clin Infect Dis* 2012 Dec;55(11):1466-1473 [[FREE Full text](#)] [doi: [10.1093/cid/cis733](https://doi.org/10.1093/cid/cis733)] [Medline: [22918991](#)]
22. Henry C, Zaizafoun M, Stock E, Ghamande S, Arroliga AC, White HD. Impact of angiotensin-converting enzyme inhibitors and statins on viral pneumonia. In: *Proc (Bayl Univ Med Cent)*. 2018 Oct 26 Presented at: *Proc (Bayl Univ Med Cent)*. ;31(4); 2018; NA p. 419-423 URL: <http://europepmc.org/abstract/MED/30948970> [doi: [10.1080/08998280.2018.1499293](https://doi.org/10.1080/08998280.2018.1499293)]
23. Lee KCH, Sewa DW, Phua GC. Potential role of statins in COVID-19. *Int J Infect Dis* 2020 Jul;96:615-617 [[FREE Full text](#)] [doi: [10.1016/j.ijid.2020.05.115](https://doi.org/10.1016/j.ijid.2020.05.115)] [Medline: [32502659](#)]
24. Kruger P, Bailey M, Bellomo R, Cooper DJ, Harward M, Higgins A, ANZ-STATInS Investigators–ANZICS Clinical Trials Group. A multicenter randomized trial of atorvastatin therapy in intensive care patients with severe sepsis. *Am J Respir Crit Care Med* 2013 Apr 01;187(7):743-750. [doi: [10.1164/rccm.201209-1718OC](https://doi.org/10.1164/rccm.201209-1718OC)] [Medline: [23348980](#)]
25. Pertzov B, Eliakim-Raz N, Atamna H, Trestioreanu A, Yahav D, Leibovici L. Hydroxymethylglutaryl-CoA reductase inhibitors (statins) for the treatment of sepsis in adults - A systematic review and meta-analysis. *Clin Microbiol Infect* 2019 Mar;25(3):280-289 [[FREE Full text](#)] [doi: [10.1016/j.cmi.2018.11.003](https://doi.org/10.1016/j.cmi.2018.11.003)] [Medline: [30472427](#)]
26. National Heart, Lung, and Blood Institute ARDS Clinical Trials Network T. Rosuvastatin for sepsis-associated acute respiratory distress syndrome. *N Engl J Med* 2014 Jun 05;370(23):2191-2200. [doi: [10.1056/nejmoa1401520](https://doi.org/10.1056/nejmoa1401520)] [Medline: [22918991](#)]

Abbreviations

ARB: angiotensin receptor blocker
ACEI: angiotensin converting enzyme inhibitor
HCT: hydrochlorothiazide
NSAID: nonsteroidal anti-inflammatory drug
DMARD: disease-modifying antirheumatic drug
RKI: Robert Koch Institute, Germany
RT-PCR: reverse transcription polymerase chain reaction
WHO: World Health Organization

Edited by T Sanchez; submitted 21.08.20; peer-reviewed by F Denis, R McGowan, S Lalmuanawma; comments to author 01.10.20; revised version received 17.10.20; accepted 16.11.20; published 14.12.20.

Please cite as:

Urbach D, Awiszus F, Leiß S, Venton T, Specht AV, Apfelbacher C
Associations of Medications With Lower Odds of Typical COVID-19 Symptoms: Cross-Sectional Symptom Surveillance Study
JMIR Public Health Surveill 2020;6(4):e22521
URL: <http://publichealth.jmir.org/2020/4/e22521/>
doi:[10.2196/22521](https://doi.org/10.2196/22521)
PMID:[33197879](https://pubmed.ncbi.nlm.nih.gov/33197879/)

©Dietmar Urbach, Friedemann Awiszus, Sven Leiß, Tamsin Venton, Alexander Vincent De Specht, Christian Apfelbacher. Originally published in *JMIR Public Health and Surveillance* (<http://publichealth.jmir.org>), 14.12.2020. This is an open-access

article distributed under the terms of the Creative Commons Attribution License (<https://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in JMIR Public Health and Surveillance, is properly cited. The complete bibliographic information, a link to the original publication on <http://publichealth.jmir.org>, as well as this copyright and license information must be included.

Original Paper

An Epidemiological Model Considering Isolation to Predict COVID-19 Trends in Tokyo, Japan: Numerical Analysis

Motoaki Utamura¹, BSc, PhD, PE; Makoto Koizumi², BSc, MSc, PhD; Seiichi Kirikami³, BSc

¹Research Laboratory for Nuclear Reactors, Tokyo Institute of Technology, Tokyo, Japan

²Hitachi Research Laboratory, Hitachi Ltd, Hitachi, Japan

³Hitachi Works, Hitachi Ltd, Hitachi, Japan

Corresponding Author:

Motoaki Utamura, BSc, PhD, PE
Research Laboratory for Nuclear Reactors
Tokyo Institute of Technology
Ookayama 2-12-1
Meguro-ku
Tokyo, 1528550
Japan
Phone: 81 3 5477 3464
Email: titech02715@gmail.com

Abstract

Background: COVID-19 currently poses a global public health threat. Although Tokyo, Japan, is no exception to this, it was initially affected by only a small-level epidemic. Nevertheless, medical collapse nearly happened since no predictive methods were available to assess infection counts. A standard susceptible-infectious-removed (SIR) epidemiological model has been widely used, but its applicability is limited often to the early phase of an epidemic in the case of a large collective population. A full numerical simulation of the entire period from beginning until end would be helpful for understanding COVID-19 trends in (separate) counts of inpatient and infectious cases and can also aid the preparation of hospital beds and development of quarantine strategies.

Objective: This study aimed to develop an epidemiological model that considers the isolation period to simulate a comprehensive trend of the initial epidemic in Tokyo that yields separate counts of inpatient and infectious cases. It was also intended to induce important corollaries of governing equations (ie, effective reproductive number) and equations for the final count.

Methods: Time-series data related to SARS-CoV-2 from February 28 to May 23, 2020, from Tokyo and antibody testing conducted by the Japanese government were adopted for this study. A novel epidemiological model based on a discrete delay differential equation (apparent time-lag model [ATLM]) was introduced. The model can predict trends in inpatient and infectious cases in the field. Various data such as daily new confirmed cases, cumulative infections, inpatients, and PCR (polymerase chain reaction) test positivity ratios were used to verify the model. This approach also derived an alternative formulation equivalent to the standard SIR model.

Results: In a typical parameter setting, the present ATLM provided 20% less infectious cases in the field compared to the standard SIR model prediction owing to isolation. The basic reproductive number was inferred as 2.30 under the condition that the time lag T from infection to detection and isolation is 14 days. Based on this, an adequate vaccine ratio to avoid an outbreak was evaluated for 57% of the population. We assessed the date (May 23) that the government declared a rescission of the state of emergency. Taking into consideration the number of infectious cases in the field, a date of 1 week later (May 30) would have been most effective. Furthermore, simulation results with a shorter time lag of $T=7$ and a larger transmission rate of $\alpha=1.43\alpha_0$ suggest that infections at large should reduce by half and inpatient numbers should be similar to those of the first wave of COVID-19.

Conclusions: A novel mathematical model was proposed and examined using SARS-CoV-2 data for Tokyo. The simulation agreed with data from the beginning of the pandemic. Shortening the period from infection to hospitalization is effective against outbreaks without rigorous public health interventions and control.

(*JMIR Public Health Surveill* 2020;6(4):e23624) doi:[10.2196/23624](https://doi.org/10.2196/23624)

KEYWORDS

coronavirus; COVID-19; epidemiological model; prediction; Tokyo; delay differential equation; SIR model; model; epidemiology; isolation; trend

Introduction

COVID-19 currently represents a global public health threat. Tokyo, Japan, is no exception, but its epidemic was small despite lacking rigorous public health intervention. The thorough behavior changes of individuals, with social distancing and avoidance of the 3 Cs [1], that is, (1) closed spaces with poor ventilation, (2) crowded places with many people, and (3) close-contact settings such as close-range conversations, appear to explain Japan's ability to slow the spread of SARS-CoV-2. Medical collapse, however, nearly occurred due to a lack of beds to accommodate the increasing number of patients [2]. Therefore, to cope with future epidemics, mathematical prediction tools are thought to be indispensable to anticipate the maximum number of patients requiring treatment.

From a clinical perspective, SARS-CoV-2 has an incubation period of 7 days, according to the World Health Organization (WHO) [3]. Other studies have reported an incubation period of 5-6 days [4-6]. Moreover, SARS-CoV-2 can be transmitted even before the onset of symptoms in infected individuals. We recognize the presence of infection acquired during the time it takes to carry out testing. Infections are not detected immediately after the infection but at a delayed timing because testing requires time. Hence, the date of true infection is some time before the date of detection. Therefore, real-time conditions cannot be known from future measurements. To take proper preventive action, a mathematical model is necessary to infer present conditions. The standard susceptible-infectious-removed (SIR) epidemic model [7] and most of its modified versions [8-10] have three compartments—the number of people who are susceptible, infectious, or have been removed either through recovery or death. Its derivative, the SEIR model [8], has another compartment, exposed (E) individuals, added to take a latency period into account. However, SARS-CoV-2 is different from most conventional infectious diseases in the point that unique symptoms are not well established yet and that patients with subclinical symptoms may be infectious [9]. Since an infectious patient cannot be identified clearly, contact between individuals in daily life needs to be limited, which creates substantial impact on social activities and the economy. Hence, it is important to locate and isolate infectious patients via testing, as isolation significantly affects the transmission. SIR/SEIR models have been standard tools used for this purpose [7,8].

SIR/SEIR models including a compartment for quarantined (Q) individuals are called SIQR [10] or SEIQR, respectively [11-13]. Some examples of derivatives include the inclusion of isolated patients in the SIR model [11], a delayed SEIQR epidemic model with a vaccination effect [12], or with quarantine and latent compartments [13]. The outbreak of SARS-CoV-2 has been analyzed by many authors in terms of quarantine rate [14-18]. Quarantine rate (ie, transition coefficient from compartment “infected” to “quarantined”) was estimated by available data under some simple assumptions [14] or using statistical methods [15], an AI (artificial intelligence) model

[16], or a sophisticated 6-compartment model [17]. Cases in Japan was analyzed by Odagaki [18]. In the actual situation, however, the PCR (polymerase chain reaction) test followed by a quarantine action was executed at a later time after the infection. As a result, it has been surmised that the actual infection situation is reflected on the daily confirmed PCR test positive number by a delay of about 2 weeks in Japan [19]. Young et al [20] developed a delayed SEIQR model including this delay effect, which was applied to the COVID-19 context by Vyasrayani and Chatterjee [21]. All patients detected by PCR testing should be quarantined but their model does not always guarantee this due to its probabilistic approach.

The SIR model essentially suits analysis for a short-term epidemic in local districts [22]. It has been widely used mainly in developing countries in need of coping with various infectious diseases where the collective population is small [22]. However, this has changed in the context of COVID-19 as spread of infection is prevailing in developed countries with a large collective population.

The limitation of these SIR derivative models lie in the fact that in the case that the collective population is large (eg, Tokyo, Japan, or Wuhan, China), previous works solved only a part of the equation rather than the whole governing equation, with the assumption that susceptible individuals are replaced by the collective population (N) [15,18]. As a result, they construct an entire solution by connecting piecewise exponential function $exp(\lambda t)$ with λ 's fitted by trend data corresponding to each piecewise period of the whole time domain. For example, Odagaki [18] fitted the trend of daily confirmed new cases in Japan in the March 1 to April 29 period with four piecewise exponential functions.

This paper attempts to propose a new epidemic model that provides not a combination of piecewise solutions but a direct simulation based on a discrete delay differential equation that includes the isolation period (hospitalization). This model is unique because of its inclusion of delay time T in the equation, and its ability to simulate a complete trend of various infectious variables from the beginning of the epidemic until the endpoint. We propose two models (PART1 and PART2). The former assumes that all infected cases lead to symptoms and eventually isolation, and was examined through various time-series data obtained from February 14 to May 23, 2020, in Tokyo [2]. The latter includes not only symptomatic but also asymptomatic cases (subclinical patients at large). Both models are capable of counting inpatient and infectious cases separately.

The relation between the fundamental reproduction number R_0 and the parameter of the present model is discussed. Furthermore, based on this knowledge, an exit strategy (a criterion for exiting the stay-at-home state of emergency) for the first wave [23] and how to cope with the coming second wave are discussed.

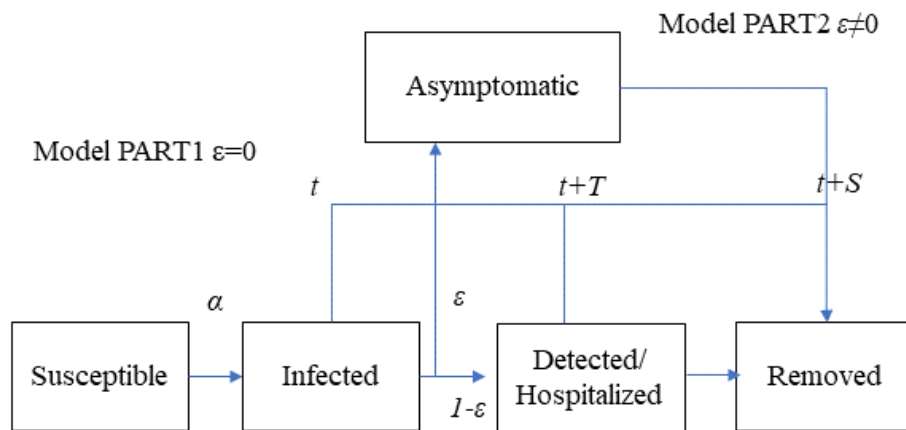
Methods

Data

For this study, we used a publicly available COVID-19 data set provided by the public health authority of the Tokyo Metropolitan Government in Japan [2]. The present epidemiological model was verified through various time-series data from February 28 to May 23, 2020, up to 2 days before the Japanese government declared a rescission of the state of emergency.

The average number of treatment days in hospital was estimated from data on the cumulative sum of discharge and deaths [2]. Simulations by the present model were examined by cumulative infections, daily new confirmed cases, detected and hospitalized, the number of inpatients, and recoveries/deaths in hospitals [2]. Numerical results were also examined via positivity ratio in PCR tests in Tokyo [2]. To establish the PART2 model, we used data from the report on antibody prevalence tests conducted by the Ministry of Health, Labor and Welfare from June 1 to 7, 2020, just after the end of the first wave in Tokyo [24]. These data were collected by public health authority announcements, were aggregate rather than individual case information, and were used only for the purpose of comparison with simulation results. Therefore, ethical approval was not considered to be required for this study.

Figure 1. Concept of the present epidemic model. Two paths from newly infected until removed (recovered/died) are shown, with symptomatic and asymptomatic paths. The portion of the former is ϵ and the latter $1-\epsilon$. The former remains infectious in the time period $[t, t+T]$ and the latter $[t, t+S]$, with $T < S$ (typically). We call the case $\epsilon=0$ model PART1 and $0 < \epsilon < 1$ model PART2. The case $\epsilon=1$ is equivalent to the standard SIR model, in which no distinction exists between symptomatic and asymptomatic cases.



where $x(t)$ is abbreviated by x , and $u(t-T)$ or $u(t-S)$ is a step function such that:

$$u(t-T) = \begin{cases} 0 & t < T \\ 1 & t \geq T \end{cases}$$

Given the number of initial infectors $x(0)$ imported from outside of the collective population, parameters S and T , and a single set of fitting parameters α and M for an entire period of epidemic, a numerical solution would be obtained.

Equation 1 is featured in an explicit inclusion of time lag parameters, S and T , which is different from the SIR model and

Prediction Models

An Epidemiological Model Considering Isolation With Delay

Figure 1 displays the concept of the present epidemiological model. For simplicity, it is assumed that once the susceptible are infected at time t with a transmission rate of α (1/day), they become infectious without delay. Whether an infected individual becomes symptomatic or asymptomatic is assumed to be intrinsically determined. The asymptomatic cases remain infectious until removed (recovery/death) at time $t+S$ while the symptomatic cases continue being infectious until hospitalization (isolation) at time $t+T$. Parameters S and T are not fitting parameters but are to be determined by empirical knowledge based on observed data. A part of infections (ϵ) is designated as asymptomatic (subclinical patients) and the rest $(1-\epsilon)$ as symptomatic. Taking cumulative infections $x(t)$ as a primary dependent variable, then the number of infectious cases at large (Q) can be counted as a sum of asymptomatic portion $\epsilon(x(t) - x(t-S))$ and symptomatic one $(1-\epsilon)(x(t) - x(t-T))$. The susceptible portion in a collective population (M) can be expressed by $1 - x(t)/M$. We assume the rate of infections (daily new cases) is proportional to the product of Q and the susceptible portion, that is, $dx(t)/dt = \alpha Q(1-x(t)/M)$. Then, $x(t)$ is governed by the following delay differential equation:

its derivatives. We designate this formulation as the apparent time-lag model (ATLM) hereafter.

The model for $\epsilon=0$ treats clinical symptoms alone and does not take asymptomatic infections (subclinical patients) into consideration. Hence, all infections are to be eventually detected and hospitalized, and equation 1 becomes equation 3, which we refer to as the epidemic model PART1:

$$\frac{dx(t)}{dt} = \alpha Q(1-x(t)/M) - \lambda x(t)$$

In the case $\epsilon=1$, an alternative formulation equivalent to a standard SIR model is obtained. In the case $0 < \epsilon < 1$, we call equation 1 the epidemic model PART2 (see Multimedia Appendix 1 for details). For the numerical integration of

equations 1-3, the fourth-order Runge-Kutta-Gill method was applied. With a time step of half a day, numerical accuracy was found to be adequate.

In the present model, the whole epidemic trend was simulated by a single delay differential equation in terms of cumulative infections x as the dependent variable.

Once x is obtained, other important variables would be evaluated in a straightforward way. For example, daily new cases dx/dt

can be calculated by the right-hand side of equation 3, the number of hospitalized $x(t-T)$ designated by Y , removed (recovered/died) $x(t-S)$ by Z , infectious cases at large $x-Y$ by Q , the number of inpatients $Y-Z$ by P and PCR test positivity ratio Q/M by Pr .

In the subsequent section, we will focus our attention on model PART1. Table 1 summarizes the variables and their corresponding expressions.

Table 1. Expressions for infection variables in terms of cumulative infections x .

Item	Variable	Expression
Cumulative onset	x	— ^a
Hospitalized	Y	$x(t-T)$
Recovered/died	Z	$x(t-S)$
Inpatients	P	$Y-Z$
Infectious cases in the field	Q	$x-Y$
Positivity ratio for PCR ^b testing	Pr	$Q/M \times 100$ (%)

^aNot applicable.

^bPCR: polymerase chain reaction.

The value of time interval T was inferred as the sum of the incubation time, detection, and testing and reporting times. As mentioned already, the WHO announced that the incubation time of SARS-CoV-2 to be 7 days [3]; in other studies in the literature, it was reported as 5-6 days [4-6]. In actuality, however, the PCR test followed by a quarantine action was executed at a later time after the infection. As a result, the actual infection situation has been said to reflect in the daily confirmed PCR test positive number after a delay of about 2 weeks in Japan, in which the time from specimen collection to reporting back to the patient is delayed. Assuming an incubation period of 5 days [25], an infectious period of presymptomatic cases of 2 days [3], and a reporting delay of PCR test results of 3 days [26], infectious patients might not be quarantined until about 14 days. Hence, in the analysis of the first wave of the SARS-CoV-2 epidemic in Tokyo, we assumed T to be 14 days.

Dimensionless Parameter and the Final Size of the Epidemic

Equation 3 can be simplified to respective time spans for $0 < t < T$ as follows:

$$x = x(0)e^{\alpha t}$$

This equation has an analytic solution, a so-called logistic function:

$$x = \frac{x(0)e^{\alpha t}}{1 - \alpha x(0)e^{\alpha t}}$$

At the beginning, equation 5 shows an exponential epidemic growth $x = x(0)e^{\alpha t} = x(0)2^{(t/\tau)}$, where τ is clinical doubling time and related to α as shown below:

$$\tau = \frac{\ln 2}{\alpha}$$

For example, with α being 0.164, the equivalent value of τ would be 4.22 days; $x/x(0)$ would become 10 in 2 weeks.

When $t > T$,

$$x = M - (M - x(0))e^{-\alpha(t-T)}$$

Normalization of equation 7 provides the following:

$$\frac{x}{M} = 1 - (1 - \frac{x(0)}{M})e^{-\alpha(t-T)}$$

where $p = x/M$ and $\sigma = t/T$. It should be noted that a single dimensionless parameter (αT) appears in equation 8 and governs epidemic behavior.

Here, we have derived a final size equation from equation 7:

$$x(\infty) = M(1 - e^{-\alpha T})$$

Solving for final size $x(\infty)$ is obtained as $Mp(\infty)$. Mathematical proof of equation 9 is available in [Multimedia Appendix 2](#).

It is interesting to note that once αT is known in the early phase of the epidemic, the final size is also known without a numerical analysis. In other words, if we happen to know the final size $x(\infty)$ as well as αT in advance, we can estimate the virtual collective population M .

Effective Reproductive Number

The effective reproductive number R_t refers to the number of infections per infectious cases in a collective population until removal. Various calculation methods have been reported [27-29] for R_0 but less for R_t . Its expression is dependent on the epidemiological model. Hattaf [27] derived R_0 for delayed SEIR model and showed delay reduces R_0 . Wallinga and Lipsitch [28] showed a framework for deriving R_0 . In the present model, possible infectors at time t exist within a time span $[t-T, t]$ whose number is Q because the infectors produced before $t-T$ are all hospitalized. Consequently, for this paper, R_t was calculated as

the ratio of daily new cases to the average number of infectants per day during time span $[t-T, t]$ as:

$$R_t = \frac{\beta N}{\gamma}$$

Combining equation 10 with equation 7 yields:

$$R_t = R_0 S(t)$$

This is consistent with the literature [17]; the effective (time-dependent) reproductive number R_t is the product of R_0 and susceptible $S(t)$ if αT is the same as R_0 .

Since no preventive measure was taken at an initial stage of the first wave of the COVID-19 pandemic from February 14 until May 23 in Tokyo, the value of R_t at the initial phase coincides with that of the basic reproductive number R_0 . Hence, noting $1 > x(0)/M$, we have:

$$R_0 = \alpha T$$

Now that dimensionless parameter αT has been identified as the basic reproductive number R_0 in the present model, R_t in equation 11 is the effective reproductive number. Furthermore, the physical meaning of R_0 was clarified, which is the product

of the ratio of time lag T and epidemic doubling time multiplied by $\ln 2$. In contrast, Makino [30] and Inaba [22] reported that the standard SIR epidemic model provides $\beta N/\gamma$ for the basic reproductive number:

$$R_0 = \beta N/\gamma$$

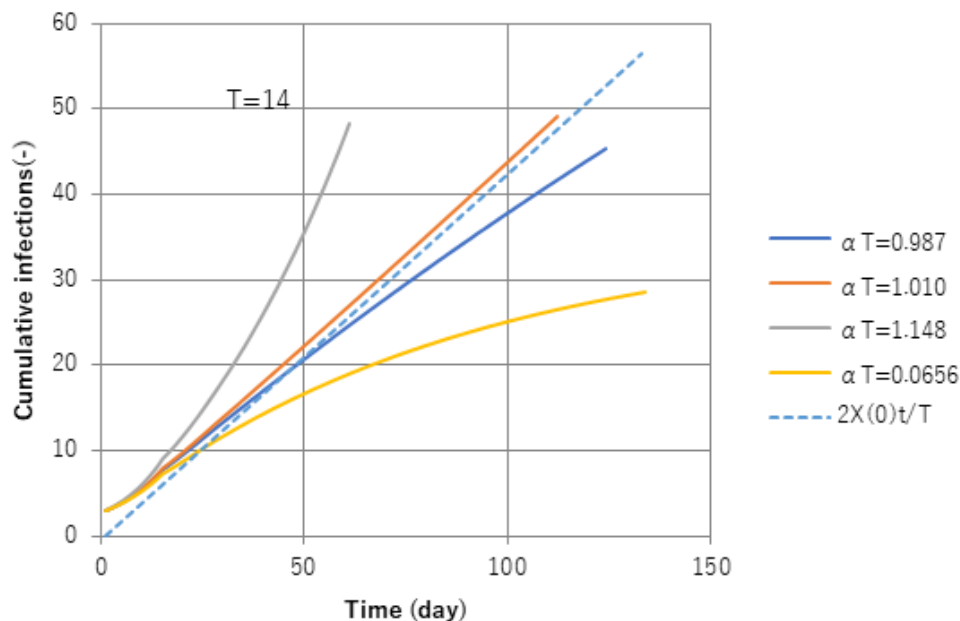
Recalling $\beta N = \alpha$ and $1/\gamma$ as the time constant, equation 13 has a meaning similar to equation 12.

Results

A Dimensionless Parameter to Characterize Early Stage Epidemic Trends

Figure 2 presents an early stage epidemic trend for the solution $x(t)$ of equation 7. The dimensionless parameter (αT) is equivalent to R_0 in equation 12. To confirm whether it is correct or not, a numerical calculation was conducted with (αT) as a parameter. It is clear in the case (αT) > 1, cumulative cases x show exponential growth of the epidemic; when (αT) < 1, they seem to be saturated. The marginal line is expressed as a broken line in Figure 2, when (αT) = 1. With these features, (αT) is identified to be R_0 .

Figure 2. Behavior of solution x with a change in the value of the parameter (αT). A clear change in the behavior of the solution $x(t)$ depending on the value of αT , a so-called bifurcation nature, is apparent. In fact, $\alpha T = 1$ is found to be a threshold with $\alpha T > 1$ causing an outbreak and $\alpha T < 1$ an endemic. This is consistent with the interpretation that αT is equal to R_0 in equation 12.



Comparison of PART1 Prediction With Observed Trend Data

Cumulative confirmed cases between February 28 and April 28 in the first wave of COVID-19 in Tokyo were adopted for the fitting of parameters, transmission rate α , and virtual collective population M . Values of other parameters, time lags from infection until isolation T and from infection until removed S , were preset as 14 and 36 based on empirical knowledge. The former has been commonly acknowledged for SARS-CoV-2 in Japan. The latter was derived as a sum of T and average length of stay (LOS) in hospital until discharge or death. The average

LOS days of inpatients was estimated to be 22 days based on the data for a total sum of discharge and deaths. Model PART1 was used. According to parameter survey calculations, α and M were selected, respectively, as 0.164 and 6200. In the following sections, the number 0.164 will be designated as α_0 and used throughout the text in later sections.

Figure 3 presents a comparison of epidemic simulation against observed data in terms of the cumulative hospitalization number (Y), the number of inpatients (P), and removed cases (recovered/died) (Z) in hospitals. Whereas observed data are available for February 28 onward, calculations started with

initial infection $x(0)=3$ on February 14, which was 14 days prior. The vertical line indicates the date April 28. Calculations succeeded in simulating observed data in general. However, Y starts overestimating data at 77 days (May 2) and afterward. It

is probable that α became smaller due to stay-at-home orders announced by metropolitan authorities 5 days earlier on April 27, by which point people's behavior changes lowered the value of transmission rate α .

Figure 3. Comparison of simulation results with data in the entire period of the first wave of COVID-19 in Tokyo. Axis represents the number of cumulative hospitalized cases (Y), the number of inpatients (P), and the number of recovered/deaths (Z). Solid lines represent simulations by model PART1. Dotted points show data observed in Tokyo, Japan.

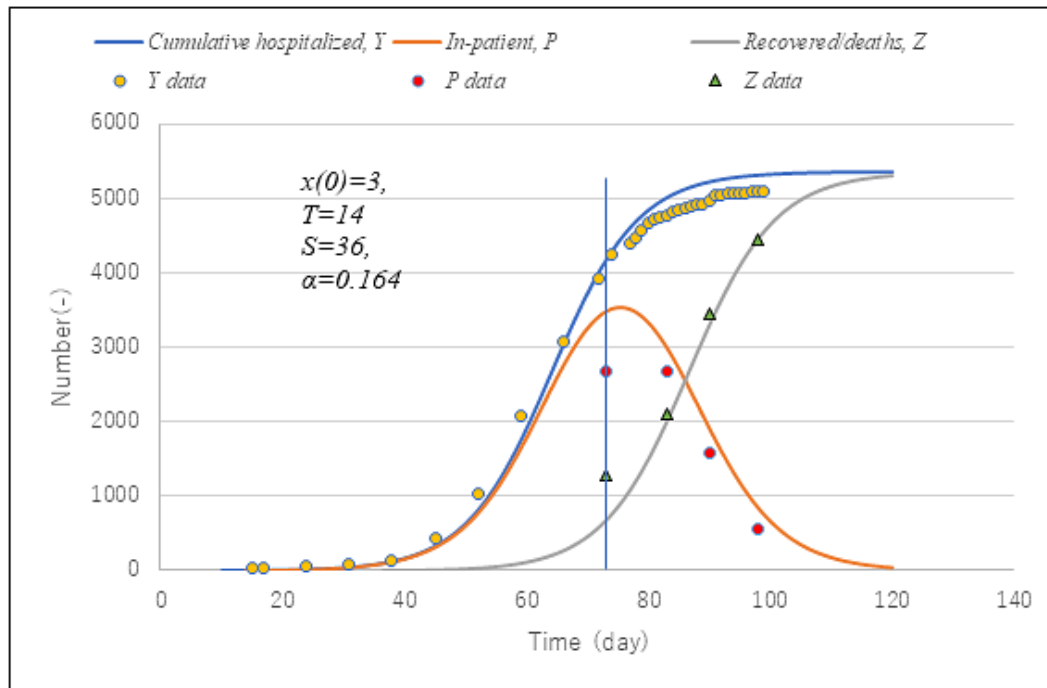


Figure 4 presents a comparison of predictions with observed data on daily new confirmed cases from February 28 to May 23, that is, the whole span of the first wave in Tokyo. Although the data show remarkable scattering, prediction succeeded in simulating their average trend at large especially toward the end of the epidemic. It should be noted that during the first wave of

the epidemic in Tokyo, the Metropolitan Tokyo Government asked those with a positive PCR test to stay in hospital until they were confirmed negative again twice. Therefore, PCR positives are equated with those who were hospitalized. Figure 5 exhibits observed trends of the positivity ratio in PCR testing compared with calculation Pr (equation 13).

Figure 4. Simulation of daily new confirmed cases compared with observed data. Model PART1 with the same parameter values as in Figure 3 was used. Note that $dY/dt=dx(t-T)/dt$ since nearly 2 weeks are needed in Japan to confirm infection by polymerase chain reaction testing.

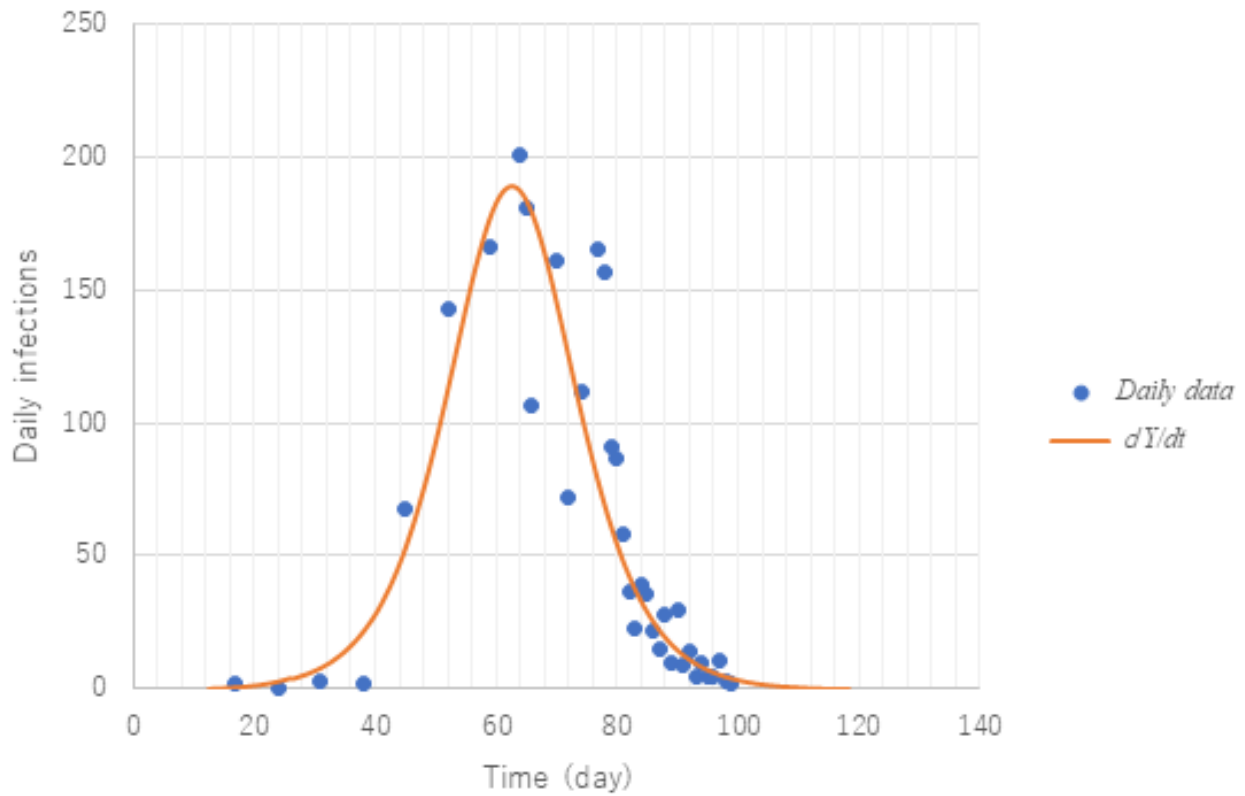
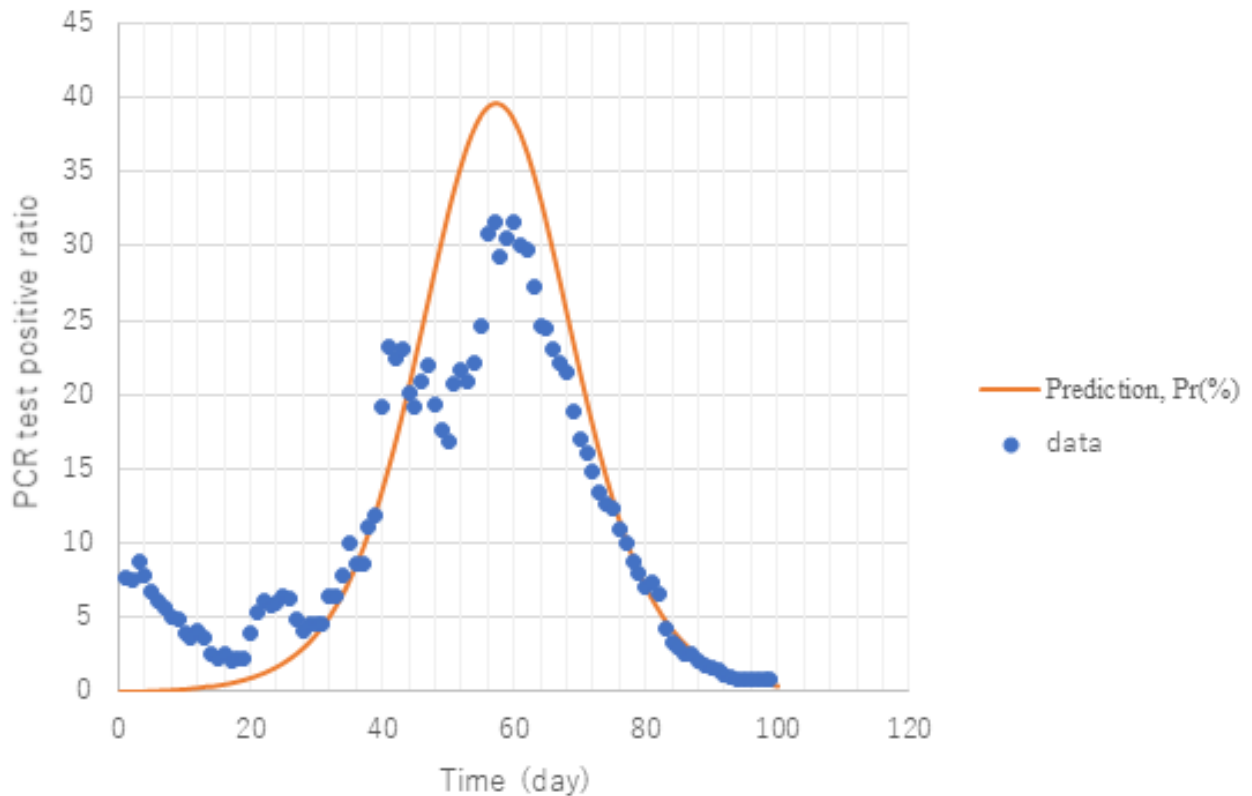


Figure 5. Simulation of positivity ratio compared with observed PCR (polymerase chain reaction) tests. Model PART1 with the same parameter values as in Figure 3 was used for the simulation.



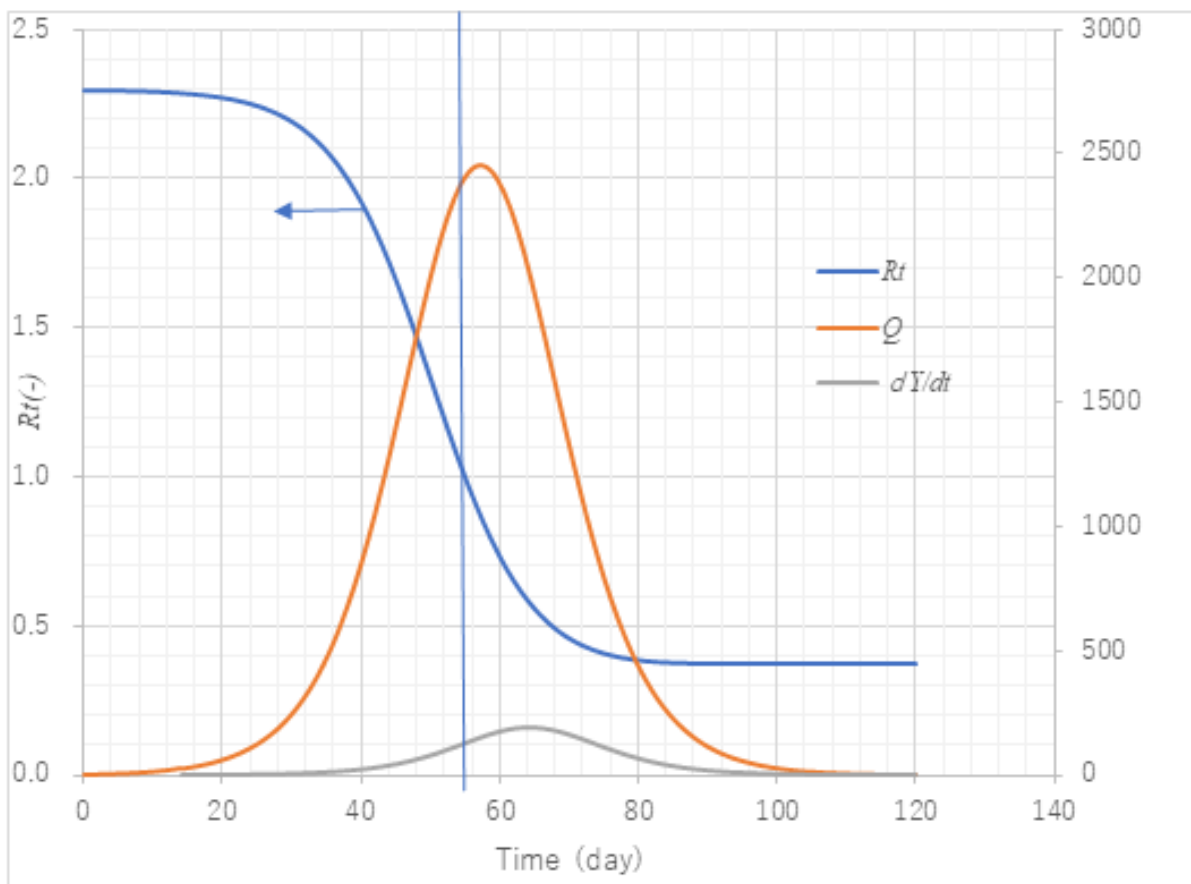
Data in the early stage might include large statistical error because of the fewer inspections conducted. Except for this period, however, data trends are well simulated in spite of the model simplicity. That is reasonable because the model counted infections with the onset of clinical symptoms, which suits the attribute of tested data. It is important to note that the agreement of numerical results with observed data implies correctness of counting infectious cases at large (Q) because of the definition of the PCR positive ratio, $Pr \equiv Q/M * 100$ (%), in the present model. Accuracy is recognized toward the endpoint of the epidemic.

Trends in the Effective Reproductive Number

Figure 6 provides trends of infectious cases at large, daily new confirmed cases, and R_t . Different from the method of past

literature, R_t in the present model is expressed by a continuous convex function. Infectious cases at large were predicted to have a peak of 2363 on day 57 (April 12), whereas the effective reproductive number R_t decreases to reach unity on day 54 (April 9). The vertical line indicates April 9 when it crosses the point where $R_t=1$. Both dates are close and reasonable. Susceptible persons remain uninfected by about 1000 susceptible individuals who are not infected. The value of $\alpha T (=R_0)$ is estimated as 2.30 using equation 11 with the transmission rate α as α_0 . The value of α_0 , however, is influenced by the Japanese government's declaration of emergency issued on April 7, which might underestimate the value at the initial stage of the epidemic. Therefore, the actual R_0 might be higher.

Figure 6. Trends of the reproductive number, R_t , infectious cases at large, and daily new confirmed cases. Model PART1 with the same parameter values as in Figure 3 was used. The value of R_t is on the left axis and the other variables, infectious cases at large (Q) and daily new confirmed cases (dY/dt), are on the right axis. The vertical line represents the date when $R_t=1$, which almost coincides with the date maximum Q is reached. This verifies the expression of R_t .



The vaccine ratio needed to avoid an outbreak in Tokyo was estimated using equation 11. To calculate the condition $R_t < 1$ at $t=0$ when the epidemic fades out, the following equation can be used:



Rearrangement provides the vaccine ratio as:



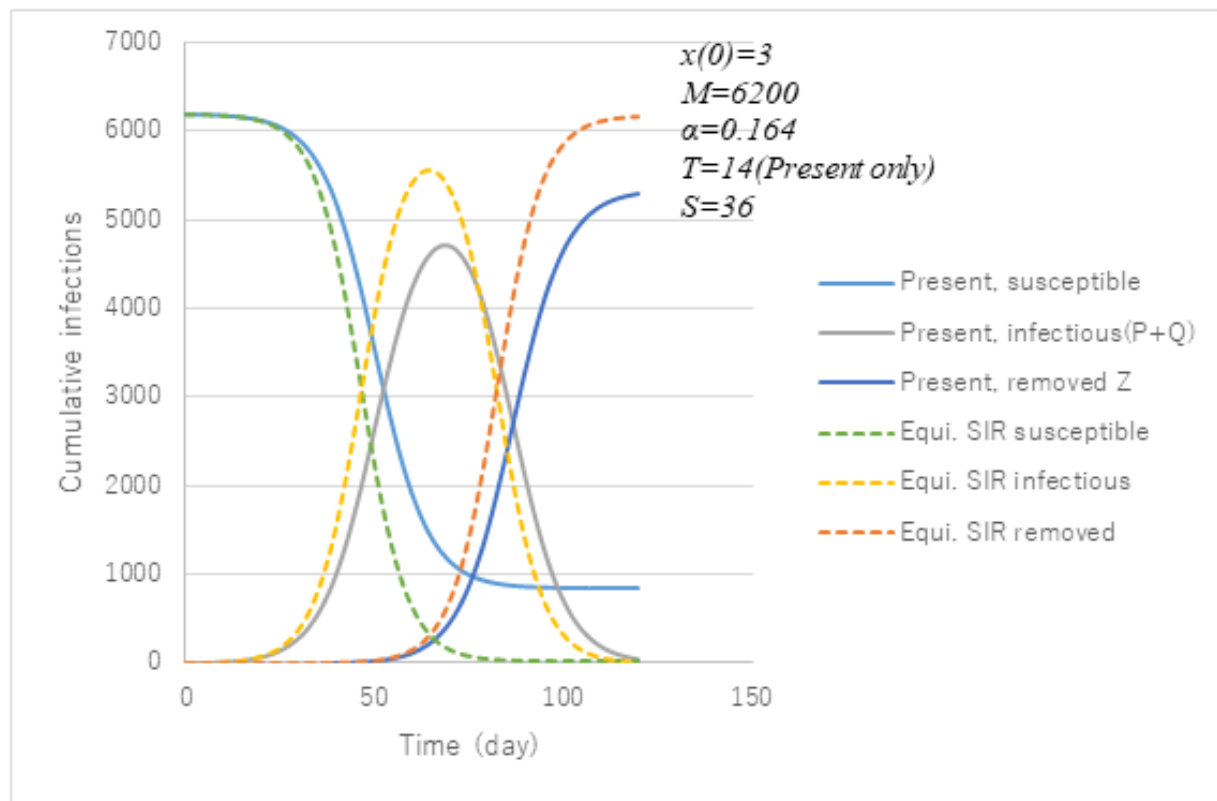
This estimate is reasonable since it is close to the value of 0.63 that Wu et al [31] obtained for the COVID-19 epidemic in Wuhan, China, as of January 23, 2020.

Comparison of ATLM With SIR

Figure 7 presents a comparison of ATLM with standard SIR epidemiological models in terms of \square under the same parameter values. Their corresponding variables in ATLM are, respectively, $P+Q$, Z , and $M-Z$. Marked differences are apparent between the two. In fact, SIR predicted that most of the

population would be infected, although ATLM left behind 1000 as uninfected. This is because the attack rate $p(\infty)$ of ATLM is 0.86, which is smaller than that of SIR (almost 1) since $\alpha T < \alpha S$. Furthermore, ATLM provides lower values by 20% for infections, which results from modeling hospitalizations before removal.

Figure 7. Comparison of simulations by the present apparent time-lag model (ATLM) with that of the standard susceptible-infectious-removed (SIR) equivalent. The results obtainable by SIR are based on equation 1 with $\epsilon=1$ shown as a broken line and those by ATLM model PART1 as a solid line. Variables for infectious, removed and susceptible in SIR model correspond to those $P+Q$, Z and $M-x$, respectively in ATLM model PART1.

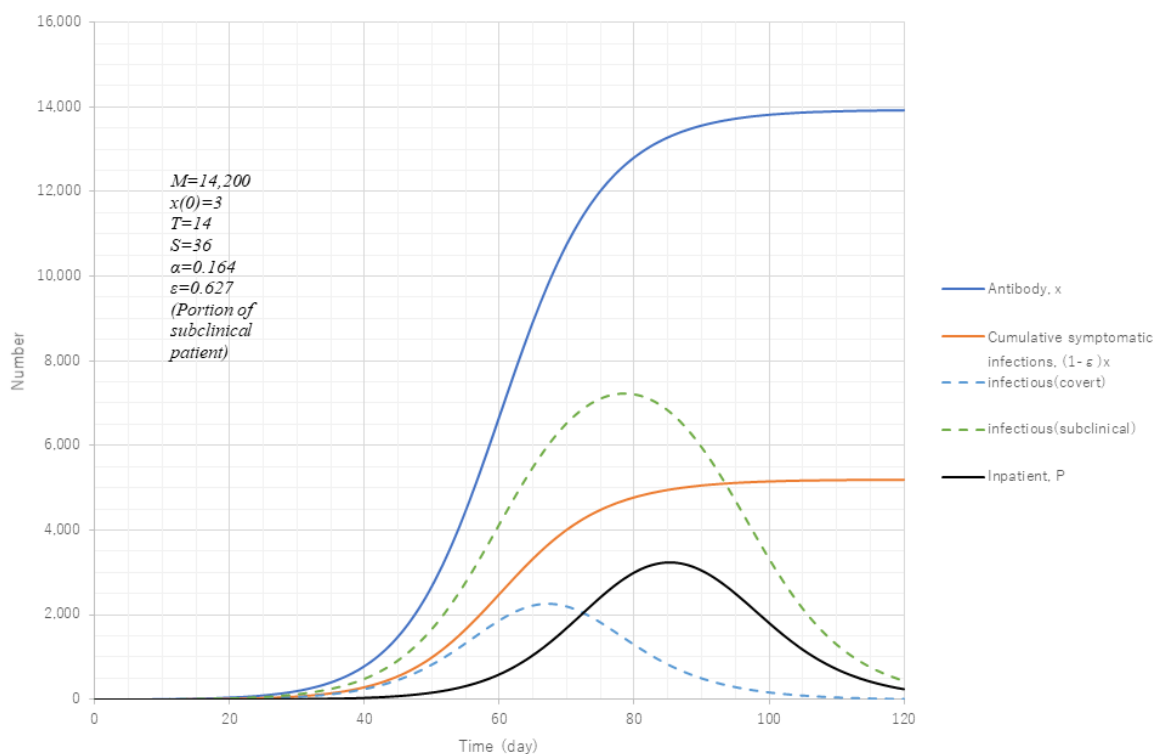


Results by PART2

According to the report of antibody prevalence tests conducted by the Ministry of Health, Labor and Welfare from June 1-7, 2020, just after the end of the first wave in Tokyo, the antibody ratio was found to be 0.10%. Since the metropolitan population is 14 million people, the number of individuals having antibodies is estimated to be 14,000. As the number of removed cases in the first wave was 5236 as of May 3 in Tokyo, this leaves 9000 in the field. Taking ϵ as $9000/14,200=0.634$ as the first estimate, simulation of the first wave was conducted using PART2 to reproduce 5200 for $(1-\epsilon)x(\infty)$ with ϵ varied. The best fit value of ϵ was 0.627.

Figure 8 presents the trends of various variables with asymptomatic cases considered. Compared with Q of PART1 in Figure 3, the peak value of the apparent spreader (ie, the symptomatic or covert patient) inferred from PART2 is 90% in size with an inpatient ratio of 92%, both of which seem to be reasonable. Apparent to asymptomatic patients, the ratio is 0.45, which is less than the relative existence ratio $(1-\epsilon)/\epsilon=0.6$. This may be due to a difference in the values of T and S . As S/T is 2.6, a silent spreader continues to reproduce infections after an apparent spreader is isolated. Further information on incubation as well as the recovery period of silent spreaders are needed for improved accuracy.

Figure 8. Model calculation with subclinical patients considered. Model PART2 (equation 1) was used. Model parameter M was determined to be 14,200 with the aid of the antibody prevalence test results. Parameter ϵ was optimized so as to give cumulative symptomatic infections, $(1-\epsilon)x$ is the same as that computed by PART1. The remaining parameter values of $x(0)$, T , S , and α were the same as PART1. Broken lines represent infectious cases as covert and subclinical separately.

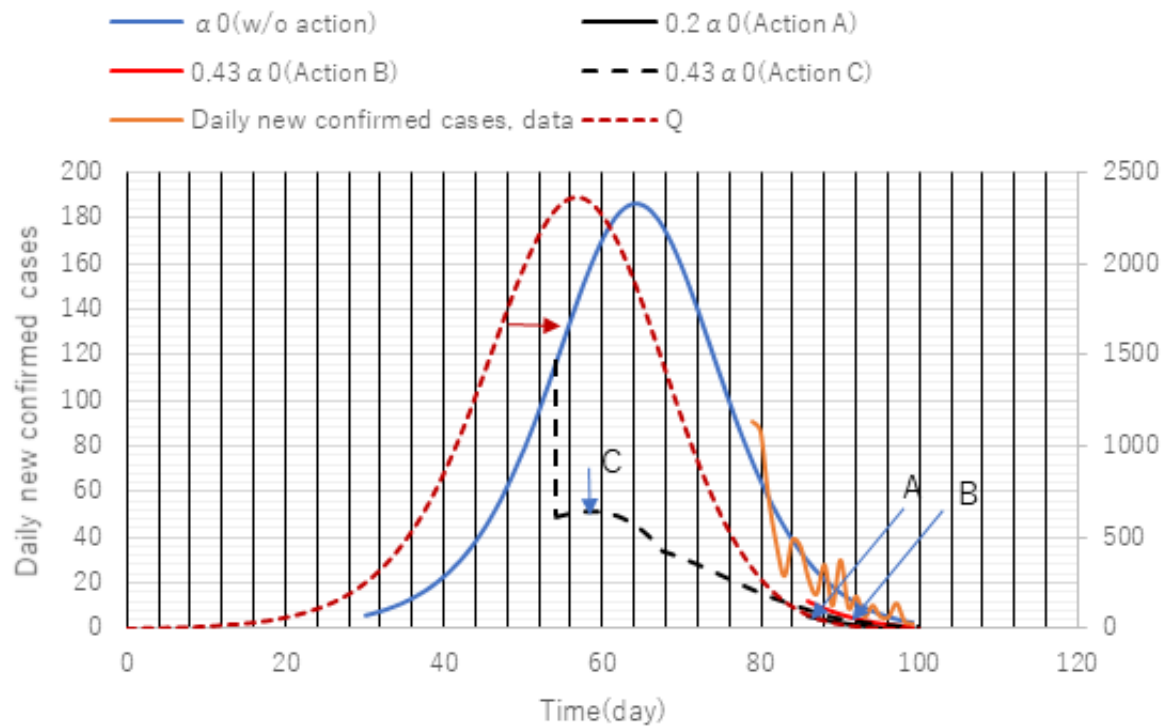


Assessment of Preventive Measures Against Spread

Toward the end of the first wave in Tokyo, strong public health interventions were conducted to prevent contact with others by 80% (stay-at-home orders issued for 80% of residents). The actual reduction in the number of contacts was estimated to be

50%-60%. The official stay-at-home announcement was declared on day 72 (April 27) after the onset of the epidemic. The simulation was tailored to assess its effects on daily new confirmed cases with and without stay-at-home actions. Results are presented in [Figure 9](#).

Figure 9. A posteriori assessment of the impact of restrained contact to reduce transmission rate, α . Stepwise change in the value of transmission rate α from α_0 to $0.2\alpha_0$ (action A) or to $0.43\alpha_0$ (action B) was applied at day 86 when the effect of the action should appear on daily new confirmed cases. Solid lines represent daily new confirmed cases (left axis) while the red broken line (infectious cases at large) to the right. It was found that “real” action A was too late in suppressing spread. If “imaginary” action C had been implemented 1 month earlier, it would have had a greater impact.



In Figure 9, actions A, B, and C are assumed public preventive measures against the spread of SARS-CoV-2. The government requested a reduction of contact between persons by 80%. In the simulation, this was modeled by a sudden decrease in the transmission rate. In a general form of $\phi\alpha_0$, ϕ ranges as follows: $0 < \phi < 1$. For instance, $0.2\alpha_0$ implies an 80% reduction of contact compared with no action ($\phi=1$).

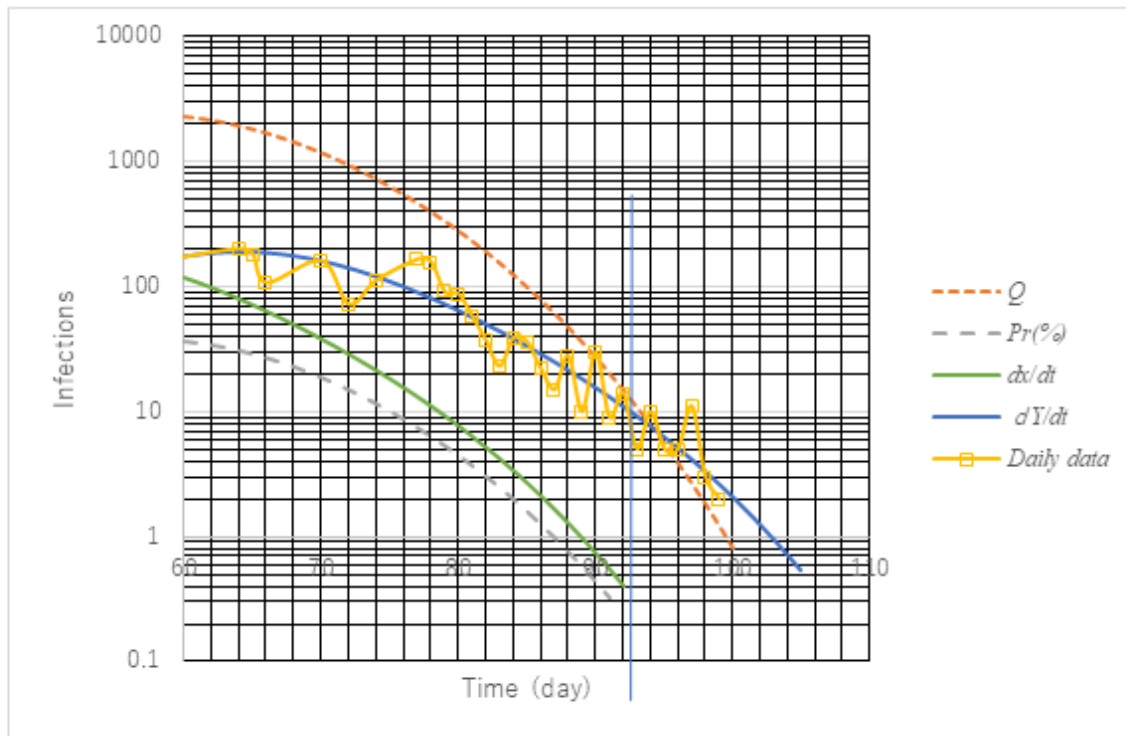
In Figure 9, simulation of daily new confirmed cases with three transmission rates of α_0 (no action), $0.43\alpha_0$ (action B), and $0.2\alpha_0$ (action A) were given together with PCR test data (orange color), with an α_0 value of 0.164. Unexpectedly, the measured data appear to follow the case with no action dY/dt , which implies that the action failed. According to the postanalysis by ATLM, the action should have been conducted earlier. Imaginary action with $0.43\alpha_0$ (action C) was taken at day 40.

Its effect appears on daily new cases data 2 weeks later (day 54) when computational action was made. A significant effect on a reduction in infections and a reduced impact on social and economic activities might have been obtained.

Assessment of Criterion for Rescission of Emergency Statement

The Japanese government issued a criterion for the rescission of the stay-at-home order for the purpose of early economic recovery, stipulating that daily infections decrease to no more than 0.5 person/day per 100,000 population. Applied to Tokyo, the criterion would yield 10 infections per day. To confirm its validity, a posterior assessment was conducted. Figure 10 presents trends of infectious variables toward the end of the first wave in Tokyo.

Figure 10. Trends of infectious variables as SARS-CoV-2 transmission declines. dx/dt represents a simulation of the actual trend of daily new cases. dY/dt was drawn with the curve dx/dt shifted to the right by 2 weeks. The daily data show daily new confirmed cases based on a positive polymerase chain reaction test. Both agreed well. The vertical blue line exhibits the date of rescission of the state of emergency declared by the Government of Japan. Then, the rescission criterion, that is, no more than 10 infections per day in terms of dY/dt , is satisfied. Infectious cases at large (Q), however, was estimated to have been 10 then according to the simulation. It should have been less than unity to aim for the extinction of SARS-CoV-2. To realize this, the rescission must be delayed by an additional week.



The criterion of 10 infections/day can be represented as dY/dt (broken line in Figure 10) at day 93 after the onset of the first wave (February 14). Noting that measured values appear with a 14-day delay, the actual number is predicted to be 0.3, according to dx/dt . This number is below unity and is low enough to meet the rescission criterion. Infectious cases at large (infectious people who are not hospitalized), however, are still around 10 according to the simulation by ATLM (red broken

line). Hence, the rescission should have been delayed by an additional 7 days (100 days afterward).

Parametric Effect of the Public Intervention Against the Coming Wave

Figures 11 and 12 show parametric effects. Calculations with parameter set of $t=14$ and $\alpha 0$ are set for the first wave and standard case. A smaller α is seen to reduce the second wave markedly.

Figure 11. Effect of transmission rate α on cumulative infections. With a reduced transmission rate α , the final size $x(\infty)$ was observed to be smaller and took longer to be attained.

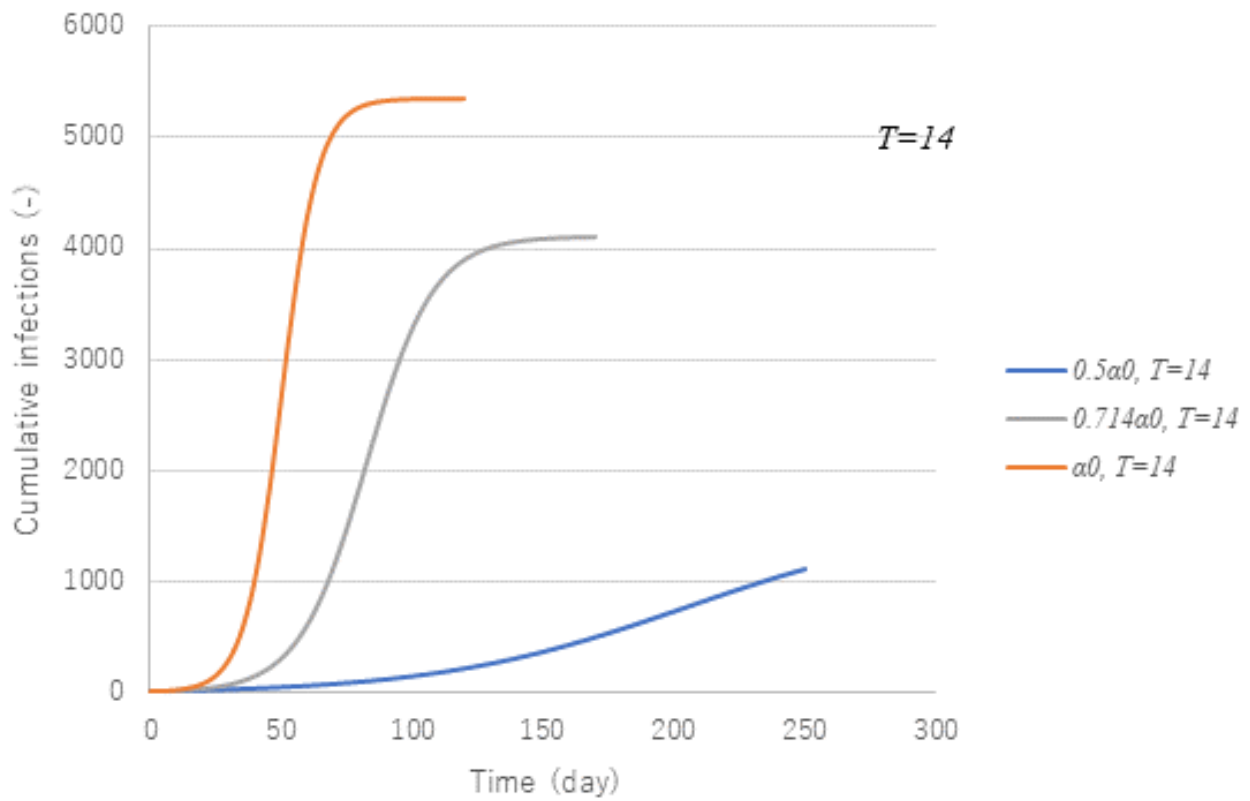
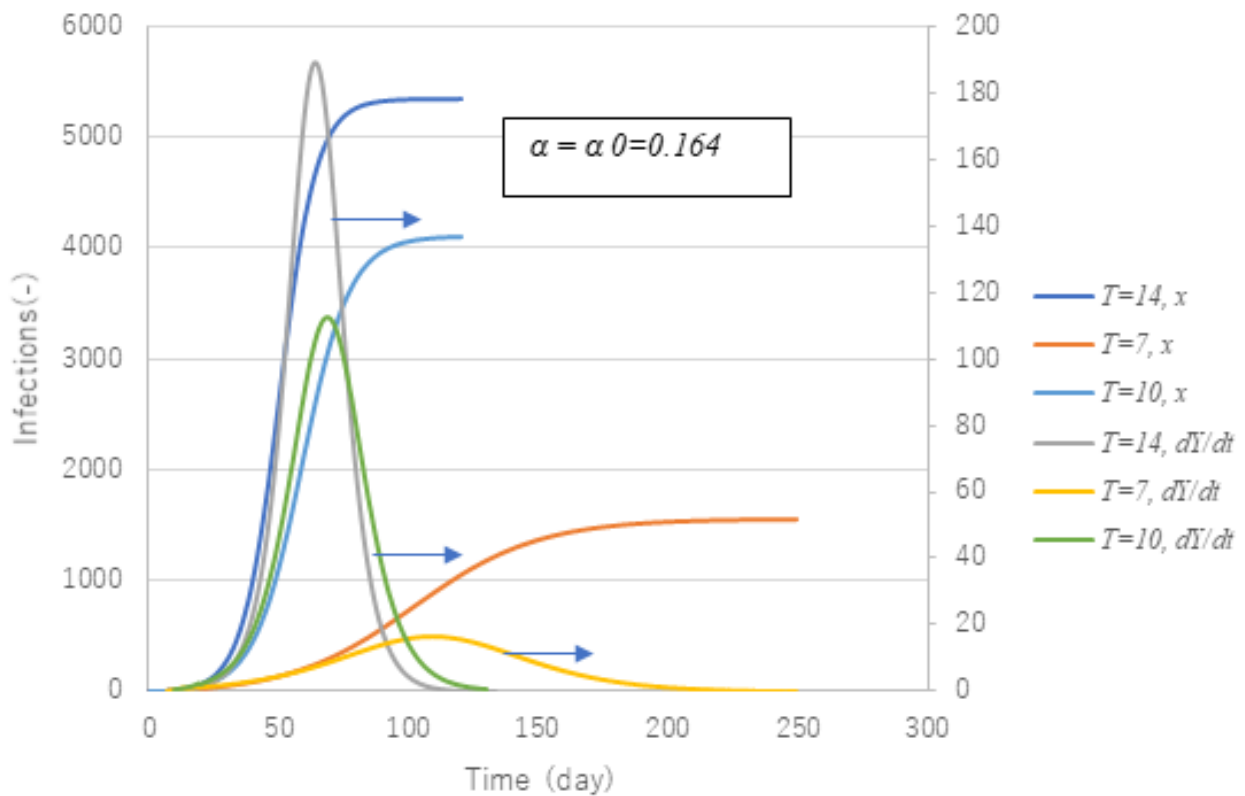


Figure 12. Effect of time lag T from infection until hospitalization on cumulative infections x (left axis) and daily new confirmed cases dY/dt (right axis). The reduction of T has a significant effect on both x and dY/dt .



A similar effect is expected by reduction of time lag T for both cumulative and daily new confirmed cases. Recovery of social and economic activities must accompany infections in a tolerable range. Consequently, a reduction in T under an increase in α is expected to be the basic policy for the coming wave followed by the first wave.

Figure 13 presents trends of cumulative cases with three (αT) values at $14\alpha_0$. $10\alpha_0$ and $7\alpha_0$ have two curves each. Among

them, the parameter set of $t=14$ and α_0 is the standard case used to simulate the first wave. It is noteworthy that the asymptotic values $x(\infty)$ of the two curves under the common αT are the same although initial increasing rates are different. It can be seen that the lower the (αT) , the smaller the magnitude of the epidemic. From this observation, three sets of parameter combinations $(\alpha T, x(\infty)/M)$ —(1.148, 0.251), (1.640, 0.665), and (2.296, 0.862)—were obtained.

Figure 13. Effect of αT on $x(\infty)$. Model PART1 was applied with parameter values same as those in Figure 3 except for transmission rate α and time lag T . Given their product αT , the final size $x(\infty)$ could be uniquely determined.

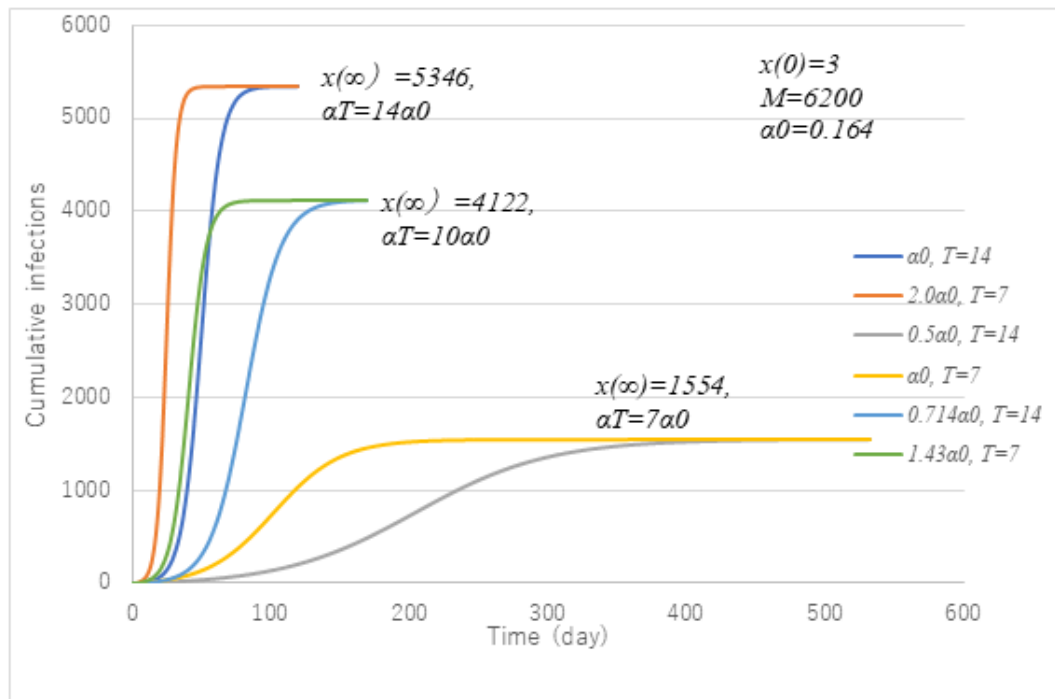


Figure 14 presents the accuracy of equation 9. Excellent agreement with numerical results is obtained. In the region $(\alpha T) < 3$ strong correlation are observed between $p(\infty)$ and (αT) , but the attack rate tends to become saturated to unity if (αT) exceeds 3.

Another point of checking is to prepare the necessary number of hospital beds. Figure 15 exhibits the number of inpatients and infectious cases at large under $\alpha t=10\alpha_0$ (ie, attack rate of 0.665). Two cases are compared with the case of the first wave

in terms of beds and infectious individuals at large. The peak number of infectious cases is seen to be reduced to half the size of the first wave for both cases. In the case of $T=7$ with $1.43\alpha_0$, the epidemic will cease 1 month earlier although the maximum number of beds is much the same as that in the first wave. Unless $T=7$ is feasible, the next choice would be $t=10$ with α_0 , which would require a reduced number of beds with a delayed transmission endpoint. From an economic point of view, $T=7$ is preferable because α is bigger. Earlier identification of infectious cases at large is essential.

Figure 14. Relationship between attack rate $p(\infty)$ and αT . The accuracy of equation 9 is verified by this numerical simulation.

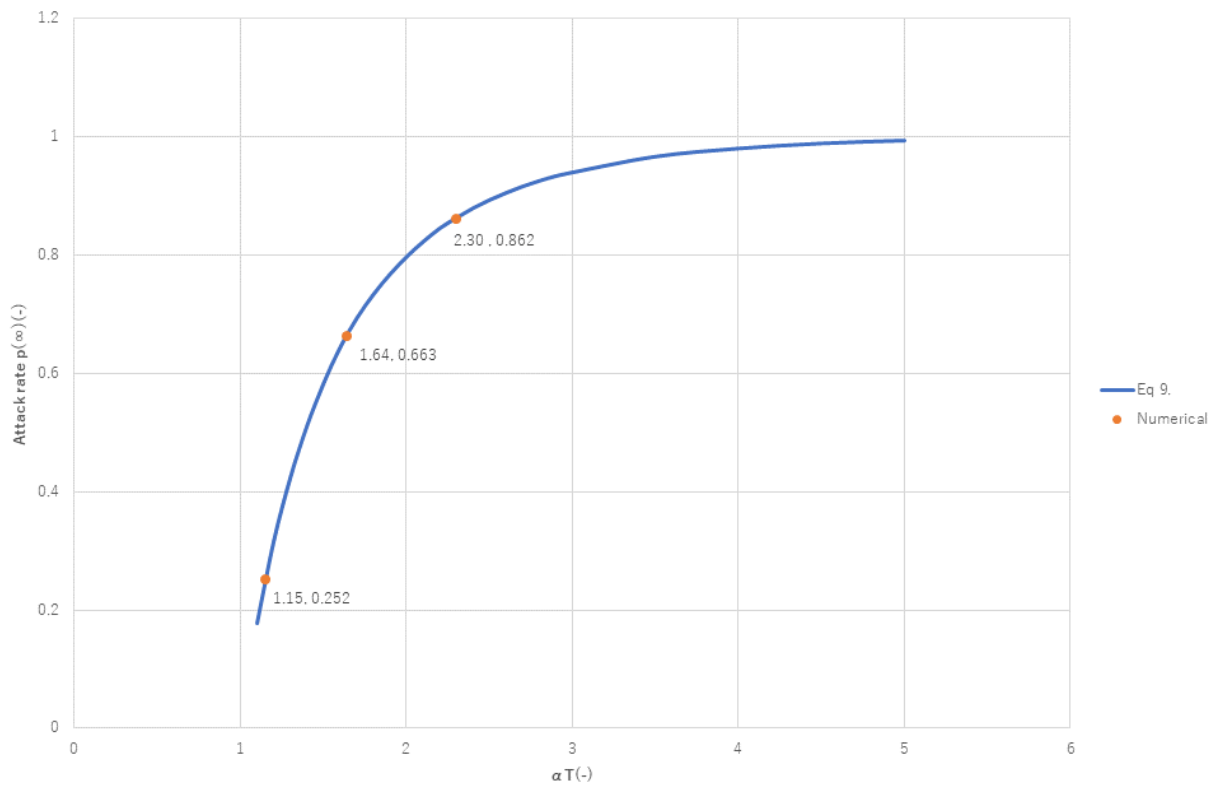
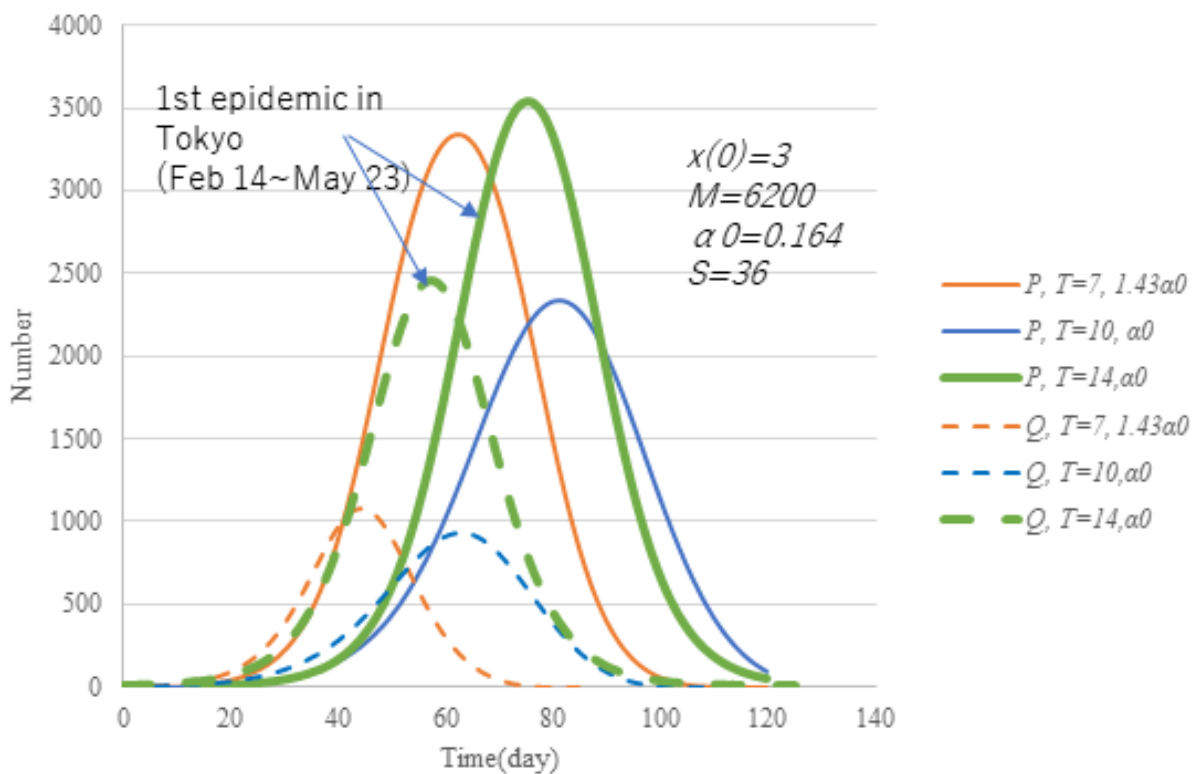


Figure 15. Effect of T on the number of inpatient and infectious cases at large under the condition of $(\alpha T)=10\alpha_0$. Model PART1 was applied with parameter values same as in Figure 3 except transmission rate α and time lag T . Solid lines represent the number of inpatients (P) and broken lines the number of infectious at large (Q). The reduction of T and an increase in α may provide a solution that reduces inpatient count and enhances economic activity.



Discussion

Principal Findings

The present epidemiological model ATLM is very simple in terms of mathematics and comprises a small number of fitting parameters, that is, the governing equation is described by only one dependent variable x (cumulative infections). Once it is solved numerically, other infection-related variables can be obtained in a straightforward manner as a function of x , as illustrated in Table 1. On the other hand, conventional approaches are complex. For example, the mathematics of SIR and its derivatives consists of multiple equations with variables depending on the number of compartments of community in the model—SEIR [8] or SIQR [10] uses four compartments, SEIQR [11-13] five, and delayed SEIQR [20] six. In essence, they have not been solved directly in the entire time span but have been approximated by a combination of piecewise exponential functions, each of which is a solution applicable to a short-term interval with a fitting parameter. For example, Odagaki [18] divided the entire time span of the first epidemic in Japan (March 1 to April 30) into four intervals and applied an SIQR model with four parameter values fitted to each interval, that is, in total 16 (4×4), whereas ATLM employs only four parameters. The accuracy of ATLM was examined by various data obtained from the first SARS-CoV-2 trends [2]. They are cumulative infections x , daily new confirmed cases dY/dt , the number of inpatients P , discharge and deaths Z , and trend of PCR positivity ratio Pr . All of these are filed in the database [2] and were simulated well by ATLM PART1. It should be noted that this was done so by a single set of four parameters for a transmission rate α of 0.164, a virtual collective population M of 6200, a time lag T of 14 from infection until isolation or hospitalization, and a time interval S of 36. ATLM succeeded in simulating the whole data trend of the first wave of the COVID-19 epidemic in Tokyo.

Among them it is noteworthy that the simulation matched the trend of the positivity ratio of PCR testing. This implies that the number of infectious cases at large was counted properly by ATLM. This fact may essentially be a base to apply simulation results to the assessment or proposal of strategies for public control of the epidemic (ie, public health interventions at the right magnitude and timing). We demonstrate two examples below.

One is the assessment of the stay-at-home order to reduce person-to-person contact by 80% declared by the metropolitan authority on April 27 (72 days after the onset of the first wave of the epidemic). Based on the prediction of infectious cases at large by the present model, the declaration should have been made 1 month earlier. If so, moderate reduction of contact by 43% would have been effective enough to reduce both inpatient and impact on social and economic activities.

The second example is the timing of the rescission of the state of emergency issued on April 7. It was actually done on May 25 based on PCR test results. However, according to the behavior of the infectious cases at large, it should have been postponed by 1 week when the calculated infectious cases at

large would reach below one at which point the epidemic would cease.

As a corollary, we induced a single dimensionless parameter (αT) from the governing equation that occupies the whole epidemic trend from onset until endpoint. More specifically, (αT) was identified as R_0 ; it also determines attack rate $p(\infty)$ and the final size of the epidemic $x(\infty)$. In practice, once we know (αT) in the early phase by data fitting, we can estimate the attack rate of the specified epidemic without numerical simulation. The value of (αT) obtained was 2.30 for the first wave of the epidemic in Tokyo; this value is close to the value of 2.20 that Li et al [6] obtained from the data taken from Wuhan, China, or the value 2.68 reported by Wu et al [31] for SARS-CoV-2.

As for the time-dependent effective reproductive number R_t , conventionally it was evaluated as a piecewise function [18]. However, ATLM expresses R_t as a function of $x(t)$ applicable to the entire period of epidemic. This is consistent with findings from the literature [17] that an effective (time-dependent) reproductive number R_t is the product of R_0 and susceptible $S(t)$.

Three parametric survey calculations for the preparation of a coming wave clarified the combination of $T=7$ and $\alpha=1.43\alpha_0$ as providing the best solution for restoring social activity, with a smaller magnitude of cumulative infections. To make T smaller in practice, faster identification and quarantine of infectious cases at large are necessary. This requires a strong task force to find infection clusters and to apply rapid testing to the greatest degree possible.

Limitations and Future Work

The present model (ATLM) has limitations. First, it is assumed that all new cases spread the infection from the time of infection t until $t+T$ isolation in hospital. In fact, a noninfectious period (exposed period) exists at the nascent stage of incubation, which may reduce the infectious period. This mechanism could be formulated within the frame of ATLM by introducing another time lag for the exposed period. It is our future task to complete this with a reliable empirical database. To do so, more information on incubation as well as recovery period of asymptomatic patients are needed for accurate modeling.

After June 2020, PCR testing was enhanced in Japan in order to suppress infectious subclinical patients as a measure of intensive cluster intervention. As a result, the number of positive PCR tests increased compared with the first wave of the epidemic and a similar number of subclinical patients as inpatients was found. Nevertheless, the maximum number of hospital beds required were less than that of the first wave in Tokyo. This may be owing to improved medical care as well as the larger portion of young patients. Postanalysis of the epidemic from June to October 2020 using general ATLM PART2 (equation 1) with information mentioned above will be our next task.

Secondly, the characteristics of the onset of clinical symptoms are stochastic. Therefore, the modeling of a preonset period and a statistical process are needed for accurate prediction. Thirdly, we assumed in the model PART2 that subclinical patients

continue to be infectious from infection to removal, which must overestimate the number of infectious cases. With more information on period S from infection until recovery for subclinical patients, modeling should be improved.

Fourthly, input parameter M (virtual collective population) introduced into ATLM as a fitting parameter enabled us to simulate the entire span of the SARS-CoV-2 trend from the beginning through to the endpoint of the epidemic in Tokyo with a single value to designate transmission rate α . However, this should be modeled in the future. In ATLM, both transmission rate α and virtual collective population M were simultaneously determined by data fitting to cumulative cases. α can be alternatively understood as the reciprocal of clinical doubling time, that is, the accelerating factor of the spread. On the other hand, M is understood as the initial susceptible, a decelerating factor for the spread if M is small. In fact, M was extremely small (~ 5000) compared to the actual population of Tokyo (14 million). This might be related to the mobility of individuals in daily life. Populations outside the flow of individuals are not susceptible. To define the invisible wall between the susceptible and the nonsusceptible would be the key to model M . This will be addressed in our future work.

In summary, this study is the first complete simulation of the first wave of the epidemic in terms of the trends associated with various SARS-CoV-2 infection parameters in Tokyo, Japan. Existing data and outbreak patterns in other countries may be better understood via the present model.

Conclusion

A novel epidemiological model (ATLM) was developed using a single delayed differential equation with explicit inclusion of the time lag associated with the isolation of infectious cases. It provides a full simulation of the various infection variables in the entire span from onset to endpoint with a small number of calculation parameters. The model was verified by various epidemic trend data (including the PCR positivity ratio) published by the Tokyo Metropolitan Government. The validity of counting infectious cases at large was checked indirectly by the coincidence of data for the PCR positivity ratio. Based on this, two practical issues about public health control of SARS-CoV-2 surfaced. One of them is the mitigation of infections by reducing social contact, declared on April 27, 2020. Based on the trend of infectious cases at large predicted by ATLM PART1, this order should have been issued 1 month earlier, which would have led to less infection as well as a reduced slowdown of social activities. The other issue is the timing of the declaration of the rescission of the state of emergency, which was issued on April 7 and rescinded on May 25. However, according to the predicted behavior of the infectious cases at large, this should have been done 1 week later when infectious cases are at <1 and the epidemic would fade out. Finally, as a control measure for a coming second wave, the combination of $T=7$ and $\alpha=1.43\alpha_0$ is recommended, which would result in enhanced social activities and a smaller magnitude of cumulative infections.

Acknowledgments

We are indebted to Mr Kazushige Tohei for his valuable comments on interpreting the numerical results. MU is a former professor of the Tokyo Institute of Technology, MK a former researcher of Hitachi Research Laboratory, Hitachi Ltd, and SK is a former engineer of Hitachi Works, Hitachi Ltd.

Authors' Contributions

MU developed and verified the epidemiological model. MK developed the computational method. SK was responsible for the mathematical aspect of ATLM. All authors have read and approve the version of the manuscript to be published.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Derivation of the general delay differential equation: consideration of silent spreaders (model PART2).

[DOCX File, 21 KB - [publichealth_v6i4e23624_app1.docx](#)]

Multimedia Appendix 2

Derivation of the final size equation.

[DOCX File, 15 KB - [publichealth_v6i4e23624_app2.docx](#)]

References

1. Important notice for preventing COVID-19 outbreaks. Ministry of Health, Labor and Welfare. 2020 Jun 27. URL: <https://www.mhlw.go.jp/content/10900000/000619576.pdf> [accessed 2020-08-05]
2. Updates on COVID-19 in Tokyo. Tokyo Metropolitan Government. 2020. URL: <https://stopcovid19.metro.tokyo.lg.jp/en> [accessed 2020-08-02]

3. Statement on the first meeting of the International Health Regulations (2005) Emergency Committee regarding the outbreak of novel coronavirus (2019-nCoV). World Health Organization. 2020 Jan 23. URL: <https://tinyurl.com/v8ulkhf> [accessed 2020-06-03]
4. Yan P, Liu S. SEIR epidemic model with delay. ANZIAM J 2009 Feb 17;48(1):119-134. [doi: [10.1017/s144618110000345x](https://doi.org/10.1017/s144618110000345x)]
5. Guan W, Ni Z, Hu Y, Liang W, Ou C, He J, et al. Clinical Characteristics of Coronavirus Disease 2019 in China. N Engl J Med 2020 Apr 30;382(18):1708-1720. [doi: [10.1056/nejmoa2002032](https://doi.org/10.1056/nejmoa2002032)]
6. Li Q, Guan X, Wu P, Wang X, Zhou L, Tong Y, et al. Early Transmission Dynamics in Wuhan, China, of Novel Coronavirus-Infected Pneumonia. N Engl J Med 2020 Mar 26;382(13):1199-1207. [doi: [10.1056/nejmoa2001316](https://doi.org/10.1056/nejmoa2001316)]
7. Kermack WO, McKendrick AG. A contribution to the mathematical theory of epidemics. Proc R Soc Lond A 1997 Jan;115(772):700-721. [doi: [10.1098/rspa.1927.0118](https://doi.org/10.1098/rspa.1927.0118)]
8. Anderson R, May R. Directly transmitted infectious diseases: control by vaccination. Science 1982 Feb 26;215(4536):1053-1060. [doi: [10.1126/science.7063839](https://doi.org/10.1126/science.7063839)] [Medline: [7063839](https://pubmed.ncbi.nlm.nih.gov/7063839/)]
9. He X, Lau EHY, Wu P, Deng X, Wang J, Hao X, et al. Temporal dynamics in viral shedding and transmissibility of COVID-19. Nat Med 2020 May;26(5):672-675 [FREE Full text] [doi: [10.1038/s41591-020-0869-5](https://doi.org/10.1038/s41591-020-0869-5)] [Medline: [32296168](https://pubmed.ncbi.nlm.nih.gov/32296168/)]
10. Hethcote H, Zhiem M, Shengbing L. Effects of quarantine in six endemic models for infectious diseases. Mathematical Biosciences 2002 Nov;180(1-2):141-160. [doi: [10.1016/s0025-5564\(02\)00111-6](https://doi.org/10.1016/s0025-5564(02)00111-6)]
11. Gerberry DJ, Milner FA. An SEIQR model for childhood diseases. J Math Biol 2009 Oct 10;59(4):535-561. [doi: [10.1007/s00285-008-0239-2](https://doi.org/10.1007/s00285-008-0239-2)] [Medline: [19066896](https://pubmed.ncbi.nlm.nih.gov/19066896/)]
12. Pei Y, Liu S, Gao S, Li S, Li C. A delayed SEIQR epidemic model with pulse vaccination and the quarantine measure. Computers & Mathematics with Applications 2009 Jul;58(1):135-145. [doi: [10.1016/j.camwa.2009.01.037](https://doi.org/10.1016/j.camwa.2009.01.037)]
13. Li T, Xue Y. Global Stability Analysis of a Delayed SEIQR Epidemic Model with Quarantine and Latent. AM 2013;04(10):109-117. [doi: [10.4236/am.2013.410a2011](https://doi.org/10.4236/am.2013.410a2011)]
14. Peng L, Yang W, Zhang D, Zhuge C, Hong L. Epidemic analysis of COVID-19 in China by dynamical modeling. medRxiv. Preprint posted online February 18, 2020 [FREE Full text] [doi: [10.1101/2020.02.16.20023465](https://doi.org/10.1101/2020.02.16.20023465)]
15. Yuan HY, Mao A, Han G, Huan H, Pfeiffer D. Effectiveness of quarantine measure on transmission dynamics of COVID-19 in Hong Kong. medRxiv. Preprint posted online April 11, 2020 [FREE Full text] [doi: [10.1101/2020.04.09.20059006](https://doi.org/10.1101/2020.04.09.20059006)]
16. Dandekar R, Barbastathis G. Quantifying the effect of quarantine control in Covid-19 infectious spread using machine learning. medRxiv. Preprint posted online April 06, 2020 [FREE Full text] [doi: [10.1101/2020.04.03.20052084](https://doi.org/10.1101/2020.04.03.20052084)]
17. Aronna MS, Guglielmi R, Moschen LM. A model for COVID-19 with isolation, quarantine and testing as control measures. medRxiv. Preprint posted online May 29, 2020 [FREE Full text] [doi: [10.1101/2020.05.29.20116897](https://doi.org/10.1101/2020.05.29.20116897)]
18. Odagaki T. Analysis of the outbreak of COVID-19 in Japan on the basis of an SIQR model. medRxiv. Preprint posted online June 05, 2020 [FREE Full text] [doi: [10.1101/2020.06.02.20117341](https://doi.org/10.1101/2020.06.02.20117341)]
19. Arrangement of persons subject to administrative inspection (draft). Ministry of Health, Labor and Welfare. 2020 Jul 14. URL: <https://www.mhlw.go.jp/content/10900000/000649238.pdf> [accessed 2020-08-02]
20. Young LS, Ruschel S, Yanchuk S, Pereira T. Consequences of delays and imperfect implementation of isolation in epidemic control. Sci Rep 2019 Mar 05;9(1):3505 [FREE Full text] [doi: [10.1038/s41598-019-39714-0](https://doi.org/10.1038/s41598-019-39714-0)] [Medline: [30837533](https://pubmed.ncbi.nlm.nih.gov/30837533/)]
21. Vyasrayani CP, Chatterjee A. New approximations, and policy implications, from a delayed dynamic model of a fast pandemic. medRxiv. Preprint posted online April 14, 2020 [FREE Full text] [doi: [10.1101/2020.04.09.20059436](https://doi.org/10.1101/2020.04.09.20059436)]
22. Inaba H. Mathematical Models for Demography and Epidemics (in Japanese). Tokyo, Japan: University of Tokyo Press; 2004:204.
23. Basic coping policy for measures against new coronavirus infection (in Japanese). Ministry of Health, Labor and Welfare. 2020 May 25. URL: https://corona.go.jp/expert-meeting/pdf/kihon_h_0525.pdf [accessed 2020-06-25]
24. Antibody possession survey results. Ministry of Health, Labor and Welfare. 2020 Jun 16. URL: <https://www.mhlw.go.jp/content/10906000/000640184.pdf> [accessed 2020-07-15]
25. Lauer SA, Grantz KH, Bi Q, Jones FK, Zheng Q, Meredith HR, et al. The Incubation Period of Coronavirus Disease 2019 (COVID-19) From Publicly Reported Confirmed Cases: Estimation and Application. Annals of Internal Medicine 2020 May 05;172(9):577-582. [doi: [10.7326/m20-0504](https://doi.org/10.7326/m20-0504)]
26. Takada M. 3 days needed to report PCR test results (in Japanese). Nihon Keizai Shimbun Morning Edition. 2020 Aug 8. URL: [N/A](#) [accessed 2020-08-08]
27. Hattaf K, Lashari A, Louartassi YN, Yousfi N. A delayed SIR epidemic model with a general incidence rate. Electron J Qual Theory Differ Equ 2013(3):1-9. [doi: [10.14232/ejqtde.2013.1.3](https://doi.org/10.14232/ejqtde.2013.1.3)]
28. Wallinga J, Lipsitch M. How generation intervals shape the relationship between growth rates and reproductive numbers. Proc Biol Sci 2007 Feb 22;274(1609):599-604 [FREE Full text] [doi: [10.1098/rspb.2006.3754](https://doi.org/10.1098/rspb.2006.3754)] [Medline: [17476782](https://pubmed.ncbi.nlm.nih.gov/17476782/)]
29. Tang B, Wang X, Li Q, Bragazzi NL, Tang S, Xiao Y, et al. Estimation of the Transmission Risk of 2019-nCoV and Its Implication for Public Health Interventions. SSRN Journal 2020. [doi: [10.2139/ssrn.3525558](https://doi.org/10.2139/ssrn.3525558)]
30. Makino J. Science literacy after Mar 11, 2011, no. 89 (in Japanese). Science Journal KAGAKU / Iwanami Publishing Co Ltd 2020 May 10;90(5):428-432.

31. Wu J, Leung KG, Leung G. Nowcasting and forecasting the potential domestic and international spread of the 2019-nCoV outbreak originating in Wuhan, China: a modelling study. *The Lancet* 2020 Feb;395(10225):689-697. [doi: [10.1016/s0140-6736\(20\)30260-9](https://doi.org/10.1016/s0140-6736(20)30260-9)]

Abbreviations

ATLM: apparent time lag model

PCR: polymerase chain reaction

SEIR: susceptible, exposed, infectious, and removed

SIR: susceptible, infectious, and removed

SIQR: susceptible, infectious, quarantine, and removed

SEIQR: susceptible, exposed, infectious, quarantine, and removed

WHO: World Health Organization

Edited by T Sanchez; submitted 18.08.20; peer-reviewed by M Razai, S Case; comments to author 20.10.20; revised version received 06.11.20; accepted 30.11.20; published 16.12.20.

Please cite as:

Utamura M, Koizumi M, Kirikami S

An Epidemiological Model Considering Isolation to Predict COVID-19 Trends in Tokyo, Japan: Numerical Analysis

JMIR Public Health Surveill 2020;6(4):e23624

URL: <http://publichealth.jmir.org/2020/4/e23624/>

doi: [10.2196/23624](https://doi.org/10.2196/23624)

PMID: [33259325](https://pubmed.ncbi.nlm.nih.gov/33259325/)

©Motoaki Utamura, Makoto Koizumi, Seiichi Kirikami. Originally published in *JMIR Public Health and Surveillance* (<http://publichealth.jmir.org>), 16.12.2020. This is an open-access article distributed under the terms of the Creative Commons Attribution License (<https://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in *JMIR Public Health and Surveillance*, is properly cited. The complete bibliographic information, a link to the original publication on <http://publichealth.jmir.org>, as well as this copyright and license information must be included.

Original Paper

Anxiety and Sleep Disturbances Among Health Care Workers During the COVID-19 Pandemic in India: Cross-Sectional Online Survey

Bhawna Gupta¹, BDentS, MPH, PhD; Vyom Sharma², MS, MBBS; Narinder Kumar³, MS, MBBS; Akanksha Mahajan⁴, BMedSci, MD

¹Torrens University, Public Health, Melbourne, Australia

²Military Hospital and Spinal Cord Injury Centre, Pune, India

³Medanta Hospital, Lucknow, India

⁴Monash University, Melbourne, Australia

Corresponding Author:

Bhawna Gupta, BDentS, MPH, PhD

Torrens University

Public Health

196 Flinders street

Melbourne

Australia

Phone: 61 1300 575 803

Email: bhawna.gupta@laureate.edu.au

Abstract

Background: The COVID-19 pandemic caused by SARS-CoV-2 has become a serious concern among the global medical community and has resulted in an unprecedented psychological impact on health care workers, who were already working under stressful conditions.

Objective: In this study, we aimed to evaluate and measure the effects of the COVID-19 pandemic on the anxiety levels and sleep quality among health care workers in India, as well as to determine how the unavailability of personal protective equipment affects their willingness to provide patient-related care.

Methods: We conducted an online cross-sectional study using piloted, structured questionnaires with self-reported responses from 368 volunteer male and female health care workers in India. Study participants were identified through social networking platforms such as Facebook and WhatsApp. The survey evaluated the participants' degree of signs and symptoms of anxiety and sleep quality based on the 7-item Generalized Anxiety Disorder (GAD-7) scale and single-item Sleep Quality Scale, respectively. Information on the availability of personal protective equipment was collected based on responses to relevant survey questions.

Results: The majority of health care workers (126/368, 34.2%) were in the age group 45-60 years, and 52.2% (192/368) were doctors. Severe anxiety (ie, GAD-7 score >10) was observed among 7.3% (27/368) health care workers, whereas moderate, mild, and minimal anxiety was observed among 12.5% (46/368), 29.3% (108/368), and 50.8% (187/368) health care workers, respectively. Moreover, 31.5% (116/368) of the health care workers had poor-to-fair sleep quality (ie, scores <6). Univariate analysis showed female gender and inadequate availability of personal protective equipment was significantly associated with higher anxiety levels ($P=.01$ for both). Sleep disturbance was significantly associated with age <30 years ($P=.04$) and inadequate personal protective equipment ($P<.001$). Multivariable analysis showed that poorer quality of sleep was associated with higher anxiety levels ($P<.001$).

Conclusions: The COVID-19 pandemic has potentially caused significant levels of anxiety and sleep disturbances among health care workers, particularly associated with the female gender, younger age group, and inadequate availability of personal protective equipment. These factors put health care workers at constant risk of contracting the infection themselves or transmitting it to their families. Early identification of at-risk health care workers and implementation of situation-tailored mitigation measures could help alleviate the risk of long-term, serious psychological sequelae as well as reduce current anxiety levels among health care workers.

(JMIR Public Health Surveill 2020;6(4):e24206) doi:[10.2196/24206](https://doi.org/10.2196/24206)

KEYWORDS

occupational epidemiology; anxiety; GAD-7; sleep quality; health care worker; pandemic; COVID-19; online survey; sleep; mental health, personal protective equipment

Introduction

An outbreak of pneumonia of unknown origin occurred in Hubei Province in China in December 2019, and owing to its ease of transmission, it has raised several concerns across more than 200 countries, areas, and territories worldwide. The global spread of COVID-19 has resulted in the World Health Organization (WHO) declaring COVID-19 as a pandemic [1,2]. Unprecedented international and national government strategies, including a strict lockdown in India, resulted in a slow albeit steady spread of COVID-19 in India as well as other countries. However, the phased relaxation of lockdown and resumption of economic activities have now led to an explosive surge in the number of COVID-19 cases in India, with a tally of 7,494,551 cases and 114,031 resulting deaths as of October 19, 2020 [2].

Previous studies provide evidence that COVID-19 has severe impact on psychological stressors, fear and anxiety, and poor sleep outcomes [3-6]. High anxiety levels during the pandemic have been strongly associated with functional impairments, alcohol or drug coping, negative religious coping, extreme hopelessness, and passive suicidal ideation [7]. Similarly, problematic sleep is associated with adverse consequences on the patient's psychological, social, and cognitive functioning, which leads to deterioration of the overall quality of life [8].

Health care workers (HCWs, including doctors, nurses, dentists, and paramedics) are regarded as the saviors of human life; nevertheless, they remain wounded by the psychological consequences of COVID-19. Frontline workers in particular, who are directly involved in management of patients with COVID-19, are at a greater risk than others [9-11]. Initial estimates suggest that frontline HCWs account for 10%-20% of all COVID-19 diagnoses [12].

In India, with a population of approximately 1.3 billion [13] and a doctor-population ratio of 1:1800 [14], the already inadequate public health care system has crumbled during the COVID-19 pandemic, further pushing frontline HCWs to the edge. Moreover, HCWs are vulnerable to physical and psychological fatigue and poor sleep outcomes due to increased workload, physical exhaustion with irregular work schedules, frequent work shifts [15], and the occasional need to make ethically challenging decisions, including rationing of care [16-18].

They are also constantly challenged by isolation and live with an omnipresent fear of contracting the infection themselves or transmitting it to their families. This fear seems to be a major factor causing a psychological impact among HCWs, apart from separation from families, shortage of personal protective equipment (PPE), lack of essential intensive care units, as well as universally and rapidly changing guidelines on disease transmission and treatment that further add to their stress. Multiple cognitive behavioral theoretical models have suggested that the following factors contribute to the severity of health

anxiety: memory and attention process, misinterpretation of health-related stimuli, and maladaptive beliefs and behaviors [19].

Research on HCWs has revealed that approximately 50% of physicians have reported poor sleep quality during the pandemic, which may be attributed to the contagious nature of COVID-19 [15,20] and the emergency nature of their work [15]. Subjective sleep quality is defined by the satisfaction of one's overall sleep experience, including aspects of sleep initiation, sleep maintenance, sleep quantity, and refreshment upon awakening [18].

The Indian perspective on anxiety, sleep outcomes, and the availability of PPE among HCWs fighting the COVID-19 pandemic is sparse. Previous studies have provided some evidence, including a study in India that evaluated stress levels only among orthopedic surgeons by using a self-validated scale and another study that assessed anxiety and depression only among doctors and nurses [21,22]. The Indian health infrastructure is not robust enough to address and provide coping strategies for its HCWs. Moreover, significant demand and supply chain disruptions have prompted efforts to conserve the limited PPE available through extended use or reuse, thereby adding an additional source of risk and anxiety for HCWs [23].

Therefore, the true burden of psychological impact needs to be measured, and it is paramount for all levels of health care organizations to screen for HCWs who are at risk of being affected by unprecedented events such as the COVID-19 pandemic. To our knowledge, this is the first study to assess the burden of anxiety disorders and effect on sleep quality of Indian HCWs during the COVID-19 pandemic. We also evaluated the extent to which the unavailability of PPE affects the readiness of HCWs to perform patient-related care.

Methods

Study Design

We performed a cross-sectional online study with HCWs. An online survey was preferred to the traditional method of data collection, as it increases the willingness of participants to answer anxiety-driven or sensitive questions [24] and avoid standard, socially desirable responses [25]. Additionally, it allows for cost-effective and instantaneous data transmission and flexibility in participation at any time of the day or night, in turn, allowing for increased response rates.

Study Participants

The inclusion criteria for this study were (1) male and female HCWs; (2) full-time practicing doctors, nurses, dentists, and paramedic staff directly involved in providing any kind of patient-related care, including but not limited to triage, screening, diagnosis, and treatment; (3) aged over 18 years and residents of India; (4) employed at either public or private hospitals or clinics; and (5) well-versed in the English language.

The exclusion criteria were HCWs who were not on active medical duty at the time of the survey due to any leave of absence.

Sample and Data Collection

Facebook and WhatsApp were used as the sampling frame. We used a respondent-driven probability sampling method, which draws on Facebook's inherent peer network structures to encourage users to recruit other HCWs who may or may not be on Facebook [26]. The diversity of Facebook members lends itself to a stratified sampling approach that may increase the representativeness of the sample. Study participants were invited through 3 online venues: (1) public or "wall" posts on Facebook advertising our research survey on popular HCW groups (ie, virtual communities linking people with some shared interest, attribute, or cause), (2) peer referral on Facebook, and (3) WhatsApp messages sent from May 2 to May 16, 2020.

Facebook advertisement for our online survey included a headline describing the survey, a brief scholarly review of the literature on the impact of COVID-19 on HCWs, and contact details of the principal investigator. The advertisement also contained an electronic link to the research questionnaire and mentioned the time required to complete the survey (ie, approximately 5 minutes). A hyperlink to the survey was also shared.

The advertisement to participate in the survey was reposted every 3 days across a period of 2 weeks. This strategy resulted in the advertisement reappearing on the users' "news feed." It also allowed the advertisement to be posted on our friends' walls, as well as in the feeds of their friends, including those who may not be friends with us on Facebook. We also sent private messages via Facebook and WhatsApp, to remind HCWs to participate in the survey. Furthermore, we created a Facebook page to promote our research and sent out mass messages addressing the HCWs among the members of this Facebook page.

Ethical Approval

This study was performed in accordance with the ethical standards laid down in the 1964 Declaration of Helsinki and its later amendments. Ethical approvals were obtained from the ethics committee of the Armed Forces Medical College, Pune (IEC/2020/154).

We included a disclaimer in our Facebook advertisement that participation in the survey was completely voluntary and survey responses were anonymous; thus, confidentiality of all participants was fully respected. Furthermore, electronic informed consent was obtained from each participant before the start of the survey. Participants had the right to withdraw from the study at any stage without any justification. They were not provided with any incentives. Moreover, participants had the opportunity to contact the investigators of this study via Facebook or WhatsApp for any questions or concerns.

Survey Questionnaire

The self-reported online survey was created using Google Forms and included 4 sections as described below. We conducted a pilot test of the questionnaire on the first 20 study participants,

and their data have not been used in this study. Please refer [Multimedia Appendix 1](#) for the questionnaire.

Generalized Anxiety Disorder

The 7-item Generalized Anxiety Disorder (GAD-7) scale is a valid and efficient tool for screening anxiety and assessing its severity in clinical practice. It consists of 7 multiple-choice questions [27,28] that assess the frequency of anxiety symptoms over the past 2 weeks on a 4-point Likert scale, with scores of 0, 1, 2, and 3 assigned to the response categories "not at all," "several days," "more than half the days," and "nearly every day," respectively. The total GAD-7 score for the 7 items ranges from 0 to 21, with increasing scores indicating more severe functional impairments as a result of anxiety. In this study, we considered GAD-7 scores of 5, 10, and 15 as the cut-off points for mild, moderate, and severe anxiety, respectively. With a threshold score of 10, a previous study reported 89% sensitivity and 82% specificity for GAD-7 [27].

Sleep Quality Scale

A validated simple, practical, and pragmatic single-item sleep quality scale (SQS) was used to assess sleep quality [29]. It helps measure sleep quality over a 7-day recall period whereby the study participants mark an integer score from 0 to 10, according to the following 5 categories: 0, terrible; 1-3, poor; 4-6, fair; 7-9, good; and 10, excellent. When using the SQS, participants were instructed to consider the following core components of sleep quality: how many hours of sleep they had, how easily they fell asleep, how often they woke up during the night (except to go to the bathroom), how often they woke up earlier than they had to in the morning, and how refreshing their sleep was.

Availability of PPE

Two of the survey questions were specifically designed to assess the participant's anxiety about the lack of access to PPE while performing patient-related care. These questions were validated using the face validation and content validation techniques of Lawshe criterion (content validity ratio = 1) [30].

Demographic Information

Finally, participants' demographic information, including age, gender, marital status, educational level, and type of health care profession was collected via some specific survey questions.

Statistical Analysis

The descriptive analysis for demographic data and preparedness for COVID-19-related questions were expressed in percentages. The relationship between 2 categorical variables, that is, anxiety among doctors and nurses regarding age and availability of PPE were estimated using chi-square test. Multivariable analysis was used to correlate the factors influencing the prevalence of anxiety of varying severity and sleep quality, with participants' age group, gender, educational level, marital status, profession, and place of work, and availability of PPE. *P* value, odds ratio (OR), and 95% CI were determined to indicate statistical significance. Hosmer-Lemeshow index was used to assess the overall model fit. A 2-tailed *P* value of <.05 indicated statistical significance. Data were analyzed using SPSS software (v.20; IBM Corp).

Results

Demographic Characteristics

Table 1 shows the demographic characteristics of the survey participants (N=368). In all, 46% (168/368) were male and

54.3% (200/368) were female HCWs. Majority of the participants (227/368, 61.7%) were working in a tertiary care facility. A higher proportion of HCWs reported the lack of availability of satisfactory PPE (140/368, 38%) than those who reported availability of PPE (129/368, 35.1%).

Table 1. Demographic characteristics of the study population (N=368).

Characteristics	Participants, n (%)
Gender	
Male	168 (45.7)
Female	200 (54.3)
Age (years)	
<30	89 (24.2)
30-44	108 (29.3)
45-60	126 (34.2)
>60	45 (12.2)
Marital status	
Unmarried	82 (22.3)
Married	139 (37.8)
Married with children	145 (39.4)
Divorced	2 (0.5)
Education level	
High school	15 (4.1)
Graduate	161 (43.8)
Postgraduate	160 (43.4)
Doctorate	32 (8.6)
Profession	
Doctor	192 (52.2)
Nurse	140 (38)
Dentist	24 (6.5)
Paramedic	12 (3.2)

Comparative Analyses

Table 2 presents the comparative analysis of anxiety among doctors and nurses with regard to age (years) and availability of PPE. HCWs with moderate (GAD-7 score = 10) and severe

(GAD-7 score = 15) anxiety scores were considered as “high risk” for anxiety for the purpose of this analysis. The results were not statistically significant for any age group and the lack of availability of adequate-quality PPE with respect to the anxiety levels among both doctors and nurses.

Table 2. Anxiety levels among doctors and nurses with regard to age and availability of personal protective equipment, determined based on Generalized Anxiety Disorder, 7-item (GAD-7) score.

Variable	Anxiety among doctors			Anxiety among nurses		
	High risk ^a	Low risk ^b	<i>P</i> value	High risk	Low risk	<i>P</i> value
Age (years), n (%)			.75			.07
<30	8 (24.2)	25 (75.7)		7 (15.2)	39 (84.7)	
30-44	10 (17.2)	48 (82.7)		11 (25.5)	32 (74.4)	
45-60	12 (15.7)	64 (84.2)		2 (5.5)	34 (94.4)	
>60	5 (20)	20 (80)		1 (6.6)	14 (93.3)	
Availability of adequate-quality PPE^c			.13			.16
PPE not required	1 (7.6)	12 (92.3)		1 (9.09)	10 (90.9)	
Yes	11 (14.8)	63 (85.1)		3 (6.3)	43 (93.6)	
No	19 (26.3)	53 (73.6)		11 (20.3)	44 (79.6)	
Not sure	4 (12.1)	29 (87.8)		6 (21.4)	22 (78.5)	

^aGAD-7 score >10.

^bGAD-7 score <10.

^cPPE: personal protective equipment.

Univariate Analysis

Table 3 describes factors affecting anxiety and sleep quality among HCWs. Half of the HCWs (187/368, 50.8%) had minimal anxiety as determined by the GAD-7 scores. Mild, moderate, and severe anxiety levels were observed among 29.3% (108/368), 12.5% (46/368), and 7.3% (27/368) of HCWs, respectively. The sleep score was poor for 5.7% (21/368) and

fair for 25.8% (95/368) HCWs, reflecting significant sleep disturbance. In contrast, good and excellent sleep scores were observed for 56.3% (207/368) and 12.2% (45/368) HCWs.

Male HCWs had significantly minimal anxiety scores (219/368, 59.5%) than female HCWs. Moreover, there was a significant association between the female gender as well as inadequate availability of PPE and higher anxiety levels ($P=.01$ for both).

Table 3. Factors affecting anxiety and quality of sleep among health care workers (N=368).

Variables	Total	Anxiety level (based on GAD-7 ^a score)				P value	Quality of sleep				P value
		Minimal (0-4)	Mild (5-9)	Moderate (10-14)	Severe (15-21)		Poor (0-3)	Fair (4-6)	Good (7-9)	Excellent (10)	
Age (years), n (%)						.19					<.001
<30	89 (24.2)	44 (49.4)	26 (29.2)	13 (14.6)	6 (6.7)		6 (6.7)	33 (37.1)	43 (48.3)	7 (7.9)	
30-44	108 (29.3)	43 (39.8)	38 (35.2)	15 (13.9)	12 (11.1)		9 (8.3)	22 (20.4)	68 (63)	9 (8.3)	
45-60	126 (34.2)	71 (56.3)	34 (27)	15 (11.9)	6 (4.8)		3 (2.4)	35 (27.8)	70 (55.6)	18 (14.3)	
>60	45 (12.2)	29 (64.4)	10 (22.2)	3 (6.7)	3 (6.7)		3 (6.7)	5 (11.1)	26 (57.8)	11 (24.4)	
Gender						.01					.54
Male	168 (45.7)	100 (59.5)	37 (22)	20 (11.9)	11 (6.5)		9 (5.4)	41 (24.4)	93 (55.4)	25 (14.9)	
Female	200 (54.3)	87 (43.5)	71 (35.5)	26 (13)	16 (8)		12 (6)	54 (27)	114 (57)	20 (10)	
Marital Status						.41					.22
Unmarried	82 (22.2)	40 (48.8)	25 (30.5)	10 (12.2)	7 (8.5)		4 (4.9)	30 (36.6)	40 (48.8)	8 (9.8)	
Married	139 (37.7)	80 (57.6)	34 (24.5)	17 (12.2)	8 (5.8)		11 (7.9)	31 (22.3)	83 (59.7)	14 (10.1)	
Married with Children	145 (39.4)	67 (46.2)	47 (32.4)	19 (13.1)	12 (8.3)		6 (4.1)	34 (23.4)	82 (56.6)	23 (15.9)	
Divorced	2 (0.5)	0	2 (100)	0	0		0	0	2 (100)	0	
Education level						.34					.35
High school	15 (4.1)	6 (40)	7 (46.6)	2 (13.3)	0		1 (6.6)	5 (33.3)	8 (53.3)	1 (6.6)	
Graduate	161 (43.7)	81 (50.3)	51 (31.6)	19 (11.8)	10 (6.2)		9 (5.5)	51 (31.6)	80 (49.6)	21 (13)	
Postgraduate	160 (43.4)	78 (48.7)	44 (27.5)	23 (14.3)	15 (9.3)		11 (6.8)	32 (20)	98 (61.2)	19 (11.8)	
Doctorate	32 (8.6)	22 (68.75)	6 (18.7)	2 (6.2)	2 (6.2)		0	7 (21.8)	21 (65.6)	4 (12.5)	
Profession						.14					.44
Doctor	192 (52.2)	109 (56.8)	46 (24)	23 (12)	14 (7.3)		14 (7.3)	43 (22.4)	109 (56.8)	26 (13.5)	
Dentist	24 (6.5)	9 (37.5)	6 (25)	6 (25)	3 (12.5)		1 (4.2)	10 (41.7)	11 (45.8)	2 (8.3)	
Nurse	140 (38)	62 (44.3)	53 (37.9)	16 (11.4)	9 (6.4)		6 (4.3)	39 (27.9)	81 (57.9)	14 (10)	
Paramedics	12 (3.3)	7 (58.3)	3 (25)	1 (8.3)	1 (8.3)		0	3 (25)	6 (50)	3 (25)	
Place of work						.34					.64
Primary	59 (16)	26 (44.1)	18 (30.5)	9 (15.3)	6 (10.2)		4 (6.8)	12 (20.3)	34 (57.6)	9 (15.3)	
Secondary	68 (18.4)	40 (58.8)	17 (25)	4 (5.9)	7 (10.3)		4 (5.9)	20 (29.4)	40 (58.8)	4 (5.9)	
Tertiary	229 (62.2)	114 (49.8)	71 (31)	30 (13.1)	14 (6.1)		13 (5.7)	59 (25.8)	128 (55.9)	29 (12.7)	

Variables	Total	Anxiety level (based on GAD-7 ^a score)				P value	Quality of sleep				P value
		Minimal (0-4)	Mild (5-9)	Moderate (10-14)	Severe (15-21)		Poor (0-3)	Fair (4-6)	Good (7-9)	Excellent (10)	
Not a health care facility	12 (3.2)	7 (58.3)	2 (16.7)	3 (25)	0		0	4 (33.3)	5 (41.7)	3 (25)	
Availability of adequate-quality PPE^b						.01					<.001
Yes	131 (35.5)	83 (63.4)	30 (22.9)	12 (9.2)	6 (4.6)		5 (3.8)	28 (21.4)	81 (61.8)	17 (13)	
No	140 (38)	58 (41.4)	42 (30)	24 (17.1)	16 (11.4)		13 (9.3)	39 (27.9)	78 (55.7)	10 (7.1)	
Not Sure	66 (17.9)	28 (42.4)	26 (39.4)	7 (10.6)	5 (7.6)		3 (4.5)	21 (31.8)	35 (53)	7 (10.6)	
PPE not required	31 (8.4)	18 (58.1)	10 (32.3)	3 (9.7)	0		0	7 (22.6)	13 (41.9)	11 (35.5)	

^aGAD-7: Generalized Anxiety Disorder, 7-item (GAD-7) scale.

^bPPE: personal protective equipment.

Multivariable Regression Analysis

Table 4 shows a negative association between gender, marital status, education, and availability of PPE; however, these were not statistically significant ($P=.21$, $.83$, $.05$, and $.09$ respectively). Similarly, there was no significant association between age and place of work as a factor for higher anxiety

levels. A similar pattern of association was observed for sleep disturbance and the abovementioned factors, with no statistically significant association for poor sleep scores (Table 4).

Furthermore, the correlation of anxiety scores and quality of sleep scores showed a significant inverse relation, reflecting poorer quality of sleep as the GAD-7 score increased ($P<.001$; Table 5).

Table 4. Factors influencing anxiety and sleep quality among health care workers.

Variables	Anxiety symptoms (GAD-7 ^a score >10)				Sleep quality score ^b ≤3			
	β	SE	Adjusted odds ratio (95% CI)	P value	β	SE	Adjusted odds ratio (95% CI)	P value
Age (years)				.36				.20
>45	ref ^c	ref	1		ref	ref	1	
<45	.31	0.35	1.37 (0.69-2.71)		.79	0.62	2.214 (0.66-7.43)	
Gender				.21				.72
Female	ref	ref	1		-.18	0.50	1	
Male	-.39	0.31	0.68 (0.37-1.25)		ref	ref	0.84 (0.31-2.25)	
Marital status				.84				.95
Other	ref	ref	1		ref	ref	1	
Married or married with children	-.04	0.18	0.96 (0.67-1.38)		.02	0.30	0.98 (0.54-1.76)	
Education				.06				.56
Lower than graduate	ref	ref	1		ref	ref	1	
Graduate and above	-.56	0.30	0.57 (0.32-1.02)		-.26	0.47	0.77 (0.30-1.93)	
Place of work				.30				.45
Not primary HCW ^d	ref	ref	1		ref	ref	1	
Primary HCW	.18	0.17	1.19 (0.85-1.67)		.21	0.28	1.23 (0.72-2.11)	
PPE^e availability				.09				.78
No	ref	ref	1 ^f		-.18	0.63	1	
Yes	-.63	0.37	0.53 (0.25-1.10)		ref	ref	0.84 (0.24-2.86)	

^aGAD-7 score ≥10 indicates moderate-to-severe anxiety symptoms.

^bSleep quality score ≤3 indicates terrible-to-poor sleep quality.

^cref: reference value.

^dHCW: health care worker.

^ePersonal protective equipment.

^f1 indicates the reference value.

Table 5. Correlation of Generalized Anxiety Disorder, 7-item (GAD-7) scores and quality of sleep scores among health care workers.

GAD-7 ^a score	Sleep quality scale ^b				Total
	Poor (1-3)	Fair (4-6)	Good (7-9)	Excellent (10)	
Minimal (0-4)	9	25	117	36	187
Mild (6-9)	4	39	60	5	108
Moderate (10-14)	3	16	25	2	46
Severe (15-21)	5	15	5	2	27
Total	21	95	207	45	368

^aGAD-7: Generalized Anxiety Disorder, 7-item scale.

^bThe correlation is significant at $P < .001$.

Discussion

Principal Findings

This is the first online survey conducted on HCWs in India during the COVID-19 pandemic that highlights the potential

burden of anxiety, sleep outcomes, and the impact of inadequate availability of PPE. Stress and symptoms of anxiety among HCWs is not a new phenomenon, as there is ample literature on burnout among HCWs during routine professional work [31,32]. This study's findings are consistent with previous SARS outbreaks wherein HCWs reported high levels of fear of

contagion and transmitting infection to their family members, in addition to emotional disturbance, uncertainty, and stigmatization [33-37]. This paradigm of anxiety among HCWs when analyzed from the perspective of a global emergency such as the COVID-19 pandemic requires a unique approach each time.

The results of our study reflect similar trends observed in surveys conducted in China [17,38]. However, these previous studies reported relatively fewer HCWs with severe anxiety levels. This may be due to the temporal association of the timing of the surveys since these were conducted in January and February 2020, which was before the WHO's declaration of COVID-19 as a pandemic and a global health emergency. Pappa et al [39] also reported noteworthy features of anxiety and poor sleep outcomes among HCWs in their meta-analysis.

Compared to male participants, female participants found it more challenging to manage their anxiety levels, particularly regarding the inadequate availability of PPE during the COVID-19 pandemic. These results are corroborated by a UK study conducted on orthopedic members [40]. The underlying association of female gender with a higher incidence of generalized anxiety across different countries was evident in a systematic review by Remes et al [41]. The higher anxiety scores among female participants in our study could be attributed to factors such as insecurity at the workplace and mental pressure to fulfil domestic responsibilities. The differentiation of anxiety scores among doctors and nurses based on gender was not significant, which reiterates the association of the female gender with higher anxiety in situations such as the COVID-19 pandemic. Cai et al [42] comprehensively evaluated the psychological health of frontline HCWs working in Hunan province and found that female HCWs were more likely to develop effective social and personal coping strategies to mitigate stress.

In addition to the innate factors responsible for higher anxiety among females, another stressor for HCWs is the "well-being" of their families [10]. This was reflected in our study as higher anxiety scores observed among HCWs who were either married or married with children than those among unmarried HCWs, although the difference was not statistically significant. An online survey conducted by University of Arkansas for Medical Sciences to assess and ensure "well-being" of their physicians found that the primary worry of all HCWs was the safety of their families during the COVID-19 pandemic, which was regarded as a major anxiety stress factor [43]. These findings highlight the need for future studies with larger sample sizes to further explore this association.

The lack of adequate PPE, which poses a threat to self as well as the family of HCWs, was another significant factor associated with higher levels of anxiety and poor sleep outcomes. A significant number of HCWs, with the majority of them being female, admitted to the unavailability of adequate PPE resulting in a highly significant correlation with poor sleep scores and moderate-to-severe anxiety levels on the GAD-7 scale. Similar results about poor sleep outcomes among female participants have been reported in other studies [6,44]. The negative psychological impact of inadequate as well as poor-quality PPE

has been previously analyzed in the context of the health care systems in the United States of America and Asia [42,43,45]. The pivotal role of the health care administrative machinery in assuring timely provision of adequate and good-quality PPE is an essential mitigation strategy that can lower anxiety levels among HCWs. This has been implemented in Singapore and applauded globally [46].

Within the context of the Indian health care system, HCWs' education and work facility do not seem to be significant stressors even during this pandemic. A possible explanation for this observation could be their past experience of working in an already stretched and an overwhelmed health care system, which may have initiated a chain of events that might lead to them coping better in such extreme scenarios. However, we observed a trend of higher anxiety scores and poor sleep scores for HCWs employed at the primary care level that can emanate from a lack of security at workplace or unsafe working conditions and, indirectly, unavailability of adequate PPE. In addition to the enormous patient burden, an intense lockdown imposed by the government could be a trigger for anxiety for HCWs due to apprehension of closure of smaller private clinics and the issue of sustainability as compared to a tertiary or corporate health care setting.

HCWs who manifest signs and symptoms of anxiety have been observed with signs of insomnia, which is reflected by their poor or fair sleep scores. Similar findings were reported in a web-based study conducted in China [3]. Pappa et al [39], in their systematic review, emphasized the clustering of such symptoms that has been evident during the COVID-19 pandemic. Our study also revealed a similar pattern of statistically significant correlation between moderate-to-severe anxiety on the GAD-7 scale and poor-to-fair sleep scores. The conversion of one symptom to another remains a matter of debate that has been observed in earlier major outbreaks like SARS as well [47,48], although COVID-19 has surpassed the SARS outbreak with regard to case load as well as global mortality.

Future Recommendations

The adverse effects of this and many other studies highlight the need for additional multipronged psychological support [10] to be provided by hospitals and organizations employing HCWs. The stress-adaptation model may be useful when considering suitable interventions. This model describes the experience of stress as a universal response to extraordinary events and environments. Under this model, a range of normal reactions such as anxiety, depression, and sleep disturbance should not be considered pathological, but instead, reframed and realigned as adaptation mechanisms. Past strategies employed during the SARS outbreak include confidence building, distribution of informational pamphlets describing signs and support resources for anxiety and stress, as well as availability of "drop in" sessions and confidential telephone support with psychiatric staff [34]. Adequate care, emotional support, and motivation should be given to HCWs by their family and community members, as this has shown to have a positive impact on sleep outcomes and may promote adaptive coping strategies [49,50]. Moreover, immediate supervisors should always be open for

communication with an empathetic attitude towards HCWs [51].

In addition, there should be better community awareness to reduce social stigma regarding mental health [52]. Despite an extremely fragile and overburdened health care system in India, the government has initiated certain exemplary confidence-building initiatives such as an insurance scheme worth an approximate amount of US \$ 66,670 for HCWs fighting in the COVID-19 crisis [53].

Strengths and Limitations

A major strength of our study is that our survey was based on previously validated and well-established objective tools such as GAD-7 and SQS for the assessment of anxiety and sleep outcomes, respectively [28]. The online modality of our cross-sectional survey prevented the risk of COVID-19 infection via droplet or contact transmission. Furthermore, the use of respondent-driven sampling has greater external validity, as it extends the sample to all potential members of the subgroups by reaching out to participants through their social networks. This sampling method also allows reaching out to some HCWs who may otherwise be undiscoverable and challenging to reach by phone or face-to-face interviews [54].

There was a proportionate representation of nurses as well as doctors among the respondent HCWs in this study; this would likely mitigate the bias of having a higher number of doctors as in previous studies conducted in India [21]. Moreover, this study highlights the prevalence of anxiety signs and symptoms

as well as poor sleep quality in a wide spectrum of HCWs during this crucial period.

Nevertheless, this study has some limitations, including the small size convenience sample collected over a 2-week period, which limits the generalizability of the results to all HCWs across India. We also acknowledge the selection and self-reporting bias in this study, which depends on the cognitive capabilities of the respondent, the disposition of the respondent towards socially desirable responses, and situational and task-related conditions [55].

Conclusions

This study highlights the psychological impact of the COVID-19 pandemic on frontline workers. The pandemic has led to features of generalized anxiety and poor sleep quality that is significantly associated with factors such as the female gender and availability of PPE. These findings underscore the need to identify HCWs at risk at an early stage and enable comprehensive, tiered, as well as situation-tailored mitigation measures, enhancing the HCWs' psychological resilience and alleviating their vulnerability in the present pandemic conditions. Limitations of working hours, special training to manage patients with COVID-19, availability of adequate-quality PPE, along with timely and appropriate mental health support through multidisciplinary teams are vital elements of such mitigation measures. These efforts are essential because of the impact of anxiety on not only HCWs' personal well-being but also on health care delivery overall, which may be affected by the HCWs' potentially impaired decision-making ability, judgement, and attention.

Authors' Contributions

BG, VS, and NK designed and conducted the study. BG, VS, NK, and AM analyzed the data and drafted the manuscript. All authors have read and agreed to the drafted version of the manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Questionnaire administered to health care workers in this study.

[PDF File (Adobe PDF File), 227 KB - [publichealth_v6i4e24206_app1.pdf](https://publichealth.v6i4e24206.app1.pdf)]

References

1. Cucinotta D, Vanelli M. WHO declares COVID-19 a pandemic. *Acta Biomed* 2020 Mar 19;91(1):157-160 [FREE Full text] [doi: [10.23750/abm.v91i1.9397](https://doi.org/10.23750/abm.v91i1.9397)] [Medline: [32191675](https://pubmed.ncbi.nlm.nih.gov/32191675/)]
2. WHO Coronavirus Disease (COVID-19) Dashboard. World Health Organization. URL: <https://covid19.who.int/> [accessed 2020-10-19]
3. Huang Y, Zhao N. Generalized anxiety disorder, depressive symptoms and sleep quality during COVID-19 outbreak in China: a web-based cross-sectional survey. *Psychiatry Res* 2020 Jun;288:112954 [FREE Full text] [doi: [10.1016/j.psychres.2020.112954](https://doi.org/10.1016/j.psychres.2020.112954)] [Medline: [32325383](https://pubmed.ncbi.nlm.nih.gov/32325383/)]
4. Choi EPH, Hui BPH, Wan EYF. Depression and anxiety in Hong Kong during COVID-19. *Int J Environ Res Public Health* 2020 May 25;17(10) [FREE Full text] [doi: [10.3390/ijerph17103740](https://doi.org/10.3390/ijerph17103740)] [Medline: [32466251](https://pubmed.ncbi.nlm.nih.gov/32466251/)]
5. Ahorsu DK, Lin C, Imani V, Saffari M, Griffiths MD, Pakpour AH. The fear of COVID-19 scale: development and initial validation. *Int J Ment Health Addict* 2020 Mar 27;1-9 [FREE Full text] [doi: [10.1007/s11469-020-00270-8](https://doi.org/10.1007/s11469-020-00270-8)] [Medline: [32226353](https://pubmed.ncbi.nlm.nih.gov/32226353/)]

6. Jahrami H, BaHammam AS, AlGahtani H, Ebrahim A, Faris M, AlEid K, et al. The examination of sleep quality for frontline healthcare workers during the outbreak of COVID-19. *Sleep Breath* 2020 Jun 26 [FREE Full text] [doi: [10.1007/s11325-020-02135-9](https://doi.org/10.1007/s11325-020-02135-9)] [Medline: [32592021](https://pubmed.ncbi.nlm.nih.gov/32592021/)]
7. Lee SA. Coronavirus Anxiety Scale: A brief mental health screener for COVID-19 related anxiety. *Death Stud* 2020;44(7):393-401. [doi: [10.1080/07481187.2020.1748481](https://doi.org/10.1080/07481187.2020.1748481)] [Medline: [32299304](https://pubmed.ncbi.nlm.nih.gov/32299304/)]
8. Szentkirályi A, Madarász CZ, Novák M. Sleep disorders: impact on daytime functioning and quality of life. *Expert Rev Pharmacoecon Outcomes Res* 2009 Feb;9(1):49-64. [doi: [10.1586/14737167.9.1.49](https://doi.org/10.1586/14737167.9.1.49)] [Medline: [19371179](https://pubmed.ncbi.nlm.nih.gov/19371179/)]
9. Spoorthy MS, Pratapa SK, Mahant S. Mental health problems faced by healthcare workers due to the COVID-19 pandemic-A review. *Asian J Psychiatr* 2020 Jun;51:102119 [FREE Full text] [doi: [10.1016/j.ajp.2020.102119](https://doi.org/10.1016/j.ajp.2020.102119)] [Medline: [32339895](https://pubmed.ncbi.nlm.nih.gov/32339895/)]
10. Shanafelt T, Ripp J, Trockel M. Understanding and addressing sources of anxiety among health care professionals during the COVID-19 pandemic. *JAMA* 2020 Jun 02;323(21):2133-2134. [doi: [10.1001/jama.2020.5893](https://doi.org/10.1001/jama.2020.5893)] [Medline: [32259193](https://pubmed.ncbi.nlm.nih.gov/32259193/)]
11. Esakandari H, Nabi-Afjadi M, Fakkari-Afjadi J, Farahmandian N, Miresmaeili S, Bahreini E. A comprehensive review of COVID-19 characteristics. *Biol Proced Online* 2020;22:19 [FREE Full text] [doi: [10.1186/s12575-020-00128-2](https://doi.org/10.1186/s12575-020-00128-2)] [Medline: [32774178](https://pubmed.ncbi.nlm.nih.gov/32774178/)]
12. Nguyen LH, Drew DA, Graham MS, Joshi AD, Guo C, Ma W, COronavirus Pandemic Epidemiology Consortium. Risk of COVID-19 among front-line health-care workers and the general community: a prospective cohort study. *Lancet Public Health* 2020 Sep;5(9):e475-e483 [FREE Full text] [doi: [10.1016/S2468-2667\(20\)30164-X](https://doi.org/10.1016/S2468-2667(20)30164-X)] [Medline: [32745512](https://pubmed.ncbi.nlm.nih.gov/32745512/)]
13. India Population (LIVE). Worldometer. URL: <https://www.worldometers.info/world-population/india-population/> [accessed 2020-12-02]
14. Deo MG. "Doctor population ratio for India - the reality". *Indian J Med Res* 2013 Apr;137(4):632-635 [FREE Full text] [Medline: [23703329](https://pubmed.ncbi.nlm.nih.gov/23703329/)]
15. Zhang C, Yang L, Liu S, Ma S, Wang Y, Cai Z, et al. Survey of insomnia and related social psychological factors among medical staff involved in the 2019 novel coronavirus disease outbreak. *Front Psychiatry* 2020;11:306 [FREE Full text] [doi: [10.3389/fpsy.2020.00306](https://doi.org/10.3389/fpsy.2020.00306)] [Medline: [32346373](https://pubmed.ncbi.nlm.nih.gov/32346373/)]
16. Chan-Yeung M. Severe acute respiratory syndrome (SARS) and healthcare workers. *Int J Occup Environ Health* 2004;10(4):421-427. [doi: [10.1179/oe.2004.10.4.421](https://doi.org/10.1179/oe.2004.10.4.421)] [Medline: [15702757](https://pubmed.ncbi.nlm.nih.gov/15702757/)]
17. Lai J, Ma S, Wang Y, Cai Z, Hu J, Wei N, et al. Factors associated with mental health outcomes among health care workers exposed to coronavirus disease 2019. *JAMA Netw Open* 2020 Mar 02;3(3):e203976 [FREE Full text] [doi: [10.1001/jamanetworkopen.2020.3976](https://doi.org/10.1001/jamanetworkopen.2020.3976)] [Medline: [32202646](https://pubmed.ncbi.nlm.nih.gov/32202646/)]
18. Kline C. In: Gellman MD, Turner JR, editors. *Encyclopedia of Behavioral Medicine*. New York: Springer; 2013.
19. Taylor S. *The Psychology of Pandemics: Preparing for the next global outbreak of infectious disease*. ProQuest, editor: Newcastle upon Tyne, UK: Cambridge Scholars Publishing; 2019.
20. Qiu D, Yu Y, Li R, Li Y, Xiao S. Prevalence of sleep disturbances in Chinese healthcare professionals: a systematic review and meta-analysis. *Sleep Med* 2020 Mar;67:258-266. [doi: [10.1016/j.sleep.2019.01.047](https://doi.org/10.1016/j.sleep.2019.01.047)] [Medline: [31040078](https://pubmed.ncbi.nlm.nih.gov/31040078/)]
21. Wilson W, Raj JP, Rao S, Ghiya M, Nedungalaparambil NM, Mundra H, et al. Prevalence and predictors of stress, anxiety, and depression among healthcare workers managing COVID-19 pandemic in India: a nationwide observational study. *Indian J Psychol Med* 2020 Jul 06;42(4):353-358. [doi: [10.1177/0253717620933992](https://doi.org/10.1177/0253717620933992)]
22. Sahu D, Agrawal T, Rathod V, Bagaria V. Impact of COVID 19 lockdown on orthopaedic surgeons in India: A survey. *J Clin Orthop Trauma* 2020 May;11(Suppl 3):S283-S290 [FREE Full text] [doi: [10.1016/j.jcot.2020.05.007](https://doi.org/10.1016/j.jcot.2020.05.007)] [Medline: [32398918](https://pubmed.ncbi.nlm.nih.gov/32398918/)]
23. Livingston E, Desai A, Berkwitz M. Sourcing personal protective equipment during the COVID-19 pandemic. *JAMA* 2020 May 19;323(19):1912-1914. [doi: [10.1001/jama.2020.5317](https://doi.org/10.1001/jama.2020.5317)] [Medline: [32221579](https://pubmed.ncbi.nlm.nih.gov/32221579/)]
24. Tourangeau R. Survey research and societal change. *Annu Rev Psychol* 2004;55:775-801. [doi: [10.1146/annurev.psych.55.090902.142040](https://doi.org/10.1146/annurev.psych.55.090902.142040)] [Medline: [14744234](https://pubmed.ncbi.nlm.nih.gov/14744234/)]
25. Chang L, Krosnick J. National surveys via RDD telephone interviewing versus the internet: comparing sample representativeness and response quality. *Public Opin Q* 2009;73(4):641-678. [doi: [10.1093/poq/nfp075](https://doi.org/10.1093/poq/nfp075)]
26. Heckathorn DD. Respondent-driven sampling: a new approach to the study of hidden populations. *Social Problems* 1997 May;44(2):174-199. [doi: [10.2307/3096941](https://doi.org/10.2307/3096941)]
27. Spitzer RL, Kroenke K, Williams JBW, Löwe B. A brief measure for assessing generalized anxiety disorder: the GAD-7. *Arch Intern Med* 2006 May 22;166(10):1092-1097. [doi: [10.1001/archinte.166.10.1092](https://doi.org/10.1001/archinte.166.10.1092)] [Medline: [16717171](https://pubmed.ncbi.nlm.nih.gov/16717171/)]
28. Löwe B, Decker O, Müller S, Brähler E, Schellberg D, Herzog W, et al. Validation and standardization of the Generalized Anxiety Disorder Screener (GAD-7) in the general population. *Med Care* 2008 Mar;46(3):266-274. [doi: [10.1097/MLR.0b013e318160d093](https://doi.org/10.1097/MLR.0b013e318160d093)] [Medline: [18388841](https://pubmed.ncbi.nlm.nih.gov/18388841/)]
29. Snyder E, Cai B, DeMuro C, Morrison MF, Ball W. A new single-item sleep quality scale: results of psychometric evaluation in patients with chronic primary insomnia and depression. *J Clin Sleep Med* 2018 Nov 15;14(11):1849-1857 [FREE Full text] [doi: [10.5664/jcsm.7478](https://doi.org/10.5664/jcsm.7478)] [Medline: [30373688](https://pubmed.ncbi.nlm.nih.gov/30373688/)]
30. Ayre C, Scally AJ. Critical values for Lawshe's content validity ratio. *Measurement and Evaluation in Counseling and Development* 2017 Mar 08;47(1):79-86. [doi: [10.1177/0748175613513808](https://doi.org/10.1177/0748175613513808)]

31. Rotenstein LS, Torre M, Ramos MA, Rosales RC, Guille C, Sen S, et al. Prevalence of burnout among physicians: a systematic review. *JAMA* 2018 Sep 18;320(11):1131-1150 [[FREE Full text](#)] [doi: [10.1001/jama.2018.12777](https://doi.org/10.1001/jama.2018.12777)] [Medline: [30326495](https://pubmed.ncbi.nlm.nih.gov/30326495/)]
32. Dyrbye LN, Shanafelt TD, Johnson PO, Johnson LA, Satele D, West CP. A cross-sectional study exploring the relationship between burnout, absenteeism, and job performance among American nurses. *BMC Nurs* 2019;18:57 [[FREE Full text](#)] [doi: [10.1186/s12912-019-0382-7](https://doi.org/10.1186/s12912-019-0382-7)] [Medline: [31768129](https://pubmed.ncbi.nlm.nih.gov/31768129/)]
33. Maunder RG, Lancee WJ, Balderson KE, Bennett JP, Borgundvaag B, Evans S, et al. Long-term psychological and occupational effects of providing hospital healthcare during SARS outbreak. *Emerg Infect Dis* 2006 Dec;12(12):1924-1932 [[FREE Full text](#)] [doi: [10.3201/eid1212.060584](https://doi.org/10.3201/eid1212.060584)] [Medline: [17326946](https://pubmed.ncbi.nlm.nih.gov/17326946/)]
34. Maunder R, Hunter J, Vincent L, Bennett J, Peladeau N, Leszcz M, et al. The immediate psychological and occupational impact of the 2003 SARS outbreak in a teaching hospital. *CMAJ* 2003 May 13;168(10):1245-1251 [[FREE Full text](#)] [Medline: [12743065](https://pubmed.ncbi.nlm.nih.gov/12743065/)]
35. Wu KK, Chan SK, Ma TM. Posttraumatic stress after SARS. *Emerg Infect Dis* 2005 Aug;11(8):1297-1300 [[FREE Full text](#)] [doi: [10.3201/eid1108.041083](https://doi.org/10.3201/eid1108.041083)] [Medline: [16102324](https://pubmed.ncbi.nlm.nih.gov/16102324/)]
36. Lee AM, Wong JGWS, McAlonan GM, Cheung V, Cheung C, Sham PC, et al. Stress and psychological distress among SARS survivors 1 year after the outbreak. *Can J Psychiatry* 2007 Apr;52(4):233-240. [doi: [10.1177/070674370705200405](https://doi.org/10.1177/070674370705200405)] [Medline: [17500304](https://pubmed.ncbi.nlm.nih.gov/17500304/)]
37. Cao W, Fang Z, Hou G, Han M, Xu X, Dong J, et al. The psychological impact of the COVID-19 epidemic on college students in China. *Psychiatry Res* 2020 May;287:112934 [[FREE Full text](#)] [doi: [10.1016/j.psychres.2020.112934](https://doi.org/10.1016/j.psychres.2020.112934)] [Medline: [32229390](https://pubmed.ncbi.nlm.nih.gov/32229390/)]
38. Zhang W, Wang K, Yin L, Zhao W, Xue Q, Peng M, et al. Mental health and psychosocial problems of medical health workers during the COVID-19 epidemic in China. *Psychother Psychosom* 2020;89(4):242-250 [[FREE Full text](#)] [doi: [10.1159/000507639](https://doi.org/10.1159/000507639)] [Medline: [32272480](https://pubmed.ncbi.nlm.nih.gov/32272480/)]
39. Pappa S, Ntella V, Giannakas T, Giannakoulis VG, Papoutsis E, Katsaounou P. Prevalence of depression, anxiety, and insomnia among healthcare workers during the COVID-19 pandemic: A systematic review and meta-analysis. *Brain Behav Immun* 2020 Aug;88:901-907 [[FREE Full text](#)] [doi: [10.1016/j.bbi.2020.05.026](https://doi.org/10.1016/j.bbi.2020.05.026)] [Medline: [32437915](https://pubmed.ncbi.nlm.nih.gov/32437915/)]
40. Thakrar A, Raheem A, Chui K, Karam E, Wickramarachchi L, Chin K. Trauma and orthopaedic team members' mental health during the COVID-19 pandemic. *Bone & Joint Open* 2020 Jun 01;1(6):316-325. [doi: [10.1302/2633-1462.16.bjo-2020-0053.r1](https://doi.org/10.1302/2633-1462.16.bjo-2020-0053.r1)]
41. Remes O, Brayne C, van der Linde R, Lafortune L. A systematic review of reviews on the prevalence of anxiety disorders in adult populations. *Brain Behav* 2016 Jul;6(7):e00497 [[FREE Full text](#)] [doi: [10.1002/brb3.497](https://doi.org/10.1002/brb3.497)] [Medline: [27458547](https://pubmed.ncbi.nlm.nih.gov/27458547/)]
42. Cai H, Tu B, Ma J, Chen L, Fu L, Jiang Y, et al. Psychological impact and coping strategies of frontline medical staff in Hunan between January and March 2020 during the outbreak of coronavirus disease 2019 (COVID-19) in Hubei, China. *Med Sci Monit* 2020 Apr 15;26:e924171 [[FREE Full text](#)] [doi: [10.12659/MSM.924171](https://doi.org/10.12659/MSM.924171)] [Medline: [32291383](https://pubmed.ncbi.nlm.nih.gov/32291383/)]
43. Berg S. Survey: Doctors' big COVID-19 worry is keeping their families safe. *AMA - Physician Health*. 2020 May 25. URL: <https://www.ama-assn.org/practice-management/physician-health/survey-doctors-big-covid-19-worry-keeping-their-families-safe> [accessed 2020-12-09]
44. ter Horst JP, de Kloet ER, Schächinger H, Oitzl MS. Relevance of stress and female sex hormones for emotion and cognition. *Cell Mol Neurobiol* 2012 Jul;32(5):725-735 [[FREE Full text](#)] [doi: [10.1007/s10571-011-9774-2](https://doi.org/10.1007/s10571-011-9774-2)] [Medline: [22113371](https://pubmed.ncbi.nlm.nih.gov/22113371/)]
45. Wang X, Zhang X, He J. Challenges to the system of reserve medical supplies for public health emergencies: reflections on the outbreak of the severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) epidemic in China. *Biosci Trends* 2020 Mar 16;14(1):3-8 [[FREE Full text](#)] [doi: [10.5582/bst.2020.01043](https://doi.org/10.5582/bst.2020.01043)] [Medline: [32062645](https://pubmed.ncbi.nlm.nih.gov/32062645/)]
46. Wong JEL, Leo YS, Tan CC. COVID-19 in Singapore-current experience: critical global issues that require attention and action. *JAMA* 2020 Apr 07;323(13):1243-1244. [doi: [10.1001/jama.2020.2467](https://doi.org/10.1001/jama.2020.2467)] [Medline: [32077901](https://pubmed.ncbi.nlm.nih.gov/32077901/)]
47. Koh D, Lim MK, Chia SE, Ko SM, Qian F, Ng V, et al. Risk perception and impact of Severe Acute Respiratory Syndrome (SARS) on work and personal lives of healthcare workers in Singapore: what can we learn? *Med Care* 2005 Jul;43(7):676-682. [doi: [10.1097/01.mlr.0000167181.36730.cc](https://doi.org/10.1097/01.mlr.0000167181.36730.cc)] [Medline: [15970782](https://pubmed.ncbi.nlm.nih.gov/15970782/)]
48. Lancee WJ, Maunder RG, Goldbloom DS, Coauthors for the Impact of SARS Study. Prevalence of psychiatric disorders among Toronto hospital workers one to two years after the SARS outbreak. *Psychiatr Serv* 2008 Jan;59(1):91-95 [[FREE Full text](#)] [doi: [10.1176/ps.2008.59.1.91](https://doi.org/10.1176/ps.2008.59.1.91)] [Medline: [18182545](https://pubmed.ncbi.nlm.nih.gov/18182545/)]
49. Kent de Grey RG, Uchino BN, Trettevik R, Cronan S, Hogan JN. Social support and sleep: A meta-analysis. *Health Psychol* 2018 Aug;37(8):787-798. [doi: [10.1037/hea0000628](https://doi.org/10.1037/hea0000628)] [Medline: [29809022](https://pubmed.ncbi.nlm.nih.gov/29809022/)]
50. Prati G, Pietrantoni L. The relation of perceived and received social support to mental health among first responders: a meta-analytic review. *J. Community Psychol* 2010 Apr;38(3):403-417. [doi: [10.1002/jcop.20371](https://doi.org/10.1002/jcop.20371)]
51. Greenberg N, Docherty M, Gnanapragasam S, Wessely S. Managing mental health challenges faced by healthcare workers during covid-19 pandemic. *BMJ* 2020 Mar 26;368:m1211. [doi: [10.1136/bmj.m1211](https://doi.org/10.1136/bmj.m1211)] [Medline: [32217624](https://pubmed.ncbi.nlm.nih.gov/32217624/)]
52. Mohindra R, Suri V, Bhalla A, Singh SM. Issues relevant to mental health promotion in frontline health care providers managing quarantined/isolated COVID19 patients. *Asian J Psychiatr* 2020 Jun;51:102084 [[FREE Full text](#)] [doi: [10.1016/j.ajp.2020.102084](https://doi.org/10.1016/j.ajp.2020.102084)] [Medline: [32289728](https://pubmed.ncbi.nlm.nih.gov/32289728/)]

53. Pradhan Mantri Garib Kalyan Package: Insurance Scheme for Healthcare Workers Fighting COVID-19. Ministry of Health and Family Welfare. URL: <https://www.mohfw.gov.in/pdf/PMInsuranceSchemePosterC.pdf> [accessed 2012-10-20]
54. Brickman Bhutta C. Not by the Book. Sociological Methods & Research 2012 Mar 21;41(1):57-88. [doi: [10.1177/0049124112440795](https://doi.org/10.1177/0049124112440795)]
55. de Reuver M, Bouwman H. Dealing with self-report bias in mobile internet acceptance and usage studies. Information & Management 2015 Apr;52(3):287-294. [doi: [10.1016/j.im.2014.12.002](https://doi.org/10.1016/j.im.2014.12.002)]

Abbreviations

GAD-7: Generalized Anxiety Disorder 7-item (scale)

HCW: health care worker

PPE: personal protective equipment

SQS: sleep quality scale

WHO: World Health Organization

Edited by G Eysenbach; submitted 09.09.20; peer-reviewed by EPH Choi, W Zhang; comments to author 07.10.20; revised version received 20.10.20; accepted 05.12.20; published 22.12.20.

Please cite as:

Gupta B, Sharma V, Kumar N, Mahajan A

Anxiety and Sleep Disturbances Among Health Care Workers During the COVID-19 Pandemic in India: Cross-Sectional Online Survey

JMIR Public Health Surveill 2020;6(4):e24206

URL: <https://publichealth.jmir.org/2020/4/e24206>

doi: [10.2196/24206](https://doi.org/10.2196/24206)

PMID: [33284784](https://pubmed.ncbi.nlm.nih.gov/33284784/)

©Bhawna Gupta, Vyom Sharma, Narinder Kumar, Akanksha Mahajan. Originally published in JMIR Public Health and Surveillance (<http://publichealth.jmir.org>), 22.12.2020. This is an open-access article distributed under the terms of the Creative Commons Attribution License (<https://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in JMIR Public Health and Surveillance, is properly cited. The complete bibliographic information, a link to the original publication on <http://publichealth.jmir.org>, as well as this copyright and license information must be included.

Viewpoint

Canada's Decentralized "Human-Driven" Approach During the Early COVID-19 Pandemic

Gregory Hansen¹, MD, MSc, MPH; Amelie Cyr², MD

¹Jim Pattison Children's Hospital, Saskatoon, SK, Canada

²Department of Pediatrics, College of Medicine, University of Saskatchewan, Saskatoon, SK, Canada

Corresponding Author:

Gregory Hansen, MD, MSc, MPH

Jim Pattison Children's Hospital

103 Hospital Drive

Pediatric Intensive Care Unit

Saskatoon, SK, S7N 0W8

Canada

Phone: 1 306 655 1000

Email: gregory.hansen@usask.ca

Abstract

A country's early response to a pandemic is critical for controlling the disease outbreak. During the COVID-19 pandemic, a number of southeast Asian countries adopted centralized, coordinated, rapid, and comprehensive approaches that involved smart technology (the "techno-driven" approach). In comparison, Canada's approach appeared to be decentralized, uncoordinated, and slow, and it focused on educating citizens and enhancing social and human capital (the "human-driven" approach). We propose that in future pandemics, early and coordinated "techno-driven" approaches should receive more careful consideration to curtail outbreaks; however, these approaches must be balanced with protecting individuals' freedoms.

(*JMIR Public Health Surveill* 2020;6(4):e20343) doi:[10.2196/20343](https://doi.org/10.2196/20343)

KEYWORDS

COVID-19; coronavirus infection; public health

Introduction

On December 31, 2019, the World Health Organization (WHO) was alerted to a pneumonia of unknown cause in Wuhan, China [1]. In January 2020, a novel coronavirus called SARS-CoV-2 was identified, its RNA was sequenced, and a public health emergency of international concern was declared. In February, the WHO announced COVID-19 as the name of disease caused by the new coronavirus, and one month later, it characterized the outbreak of COVID-19 as a pandemic [1].

For years, the WHO has provided global leadership for pandemic preparedness and response. This organization has recognized that early and effective planning can attenuate social and economic disruption, threats to essential services, and difficulties with production levels, distribution, and shortages of supplies [2]. Consequently, the WHO has created a comprehensive framework that guides national actions with planning and coordination, pandemic disease surveillance, monitoring impact (ie, medical supplies), reducing spread of disease, and communications [3]. Inherent to the framework is the capacity to determine the pathogen's effect as early as

possible so that the proportionate response can be executed [4,5]. Determining disease severity and transmissibility through early identified cases, known as "first few hundred" studies, is key [5].

Evaluating early national responses to their first few hundred COVID-19 cases may be useful to optimize future global pandemic actions. Canada's 1st case was reported on January 25, 2020 [6], and 45 days later, its 99th case was announced. Canada's response during this critical time largely employed a "human-driven" approach, which relied on educating citizens and enhancing social and human capital [7].

In this viewpoint, we are critical of Canada's "human-driven" approach by contrasting it with key recommendations of the WHO's pandemic document [3] and "techno-driven" approaches that were effective in other countries. A "techno-driven approach" relies on top-down initiatives that mandate widespread use of smart technology [7], and it includes measures such as contact tracing apps and data collection surveillance.

Planning and Coordination

Ironically, one of Canada's most important global contributions to global health was in the midst of a long-overdue upgrade during the initial stages of the COVID-19 pandemic. The Global Public Health Intelligence Network (GPHIN) is an all-hazards software surveillance system developed by the federal government of Canada to provide situational awareness by collecting and analyzing new articles, incident reports, and media releases from multiple sources and languages [8]. The GPHIN is credited with helping identify the severe acute respiratory syndrome (SARS) and H1N1 influenza outbreaks, and the WHO is one of its many subscribers; however, its effectiveness may have been attenuated by an outdated algorithm and limited data sources [9]. Instead, a private Canadian software company called BlueDot was not only the first to warn of the new illness [10] but also predicted the next 11 cities that would be affected. Because inadequate funding and an aging network have both been cited as challenges for the GPHIN, collaborating with nongovernmental big data research centers may be an alternative for the future.

On January 15, 2020, when only a few cases of COVID-19 had been reported globally, the Public Health Agency of Canada

(PHAC) triggered the federal, provincial, and territorial Public Health Response Plan for Biological Events and activated the Health Portfolio Operations Centre [11]. The former was intended to facilitate efficient, evidence-based, timely, consistent, and coordinated approaches across jurisdictions, while the latter acted as the point of contact for operational communications and emergency management governance support [12]. As COVID-19 spread globally, its identity began to take shape: asymptomatic carrier transmission (February 21) [13], basic reproduction numbers ranging from 1.4 to 3.11 (January 23) [14,15], a case fatality ratio of 3.5%, and a mean incubation period of approximately 5 days (February 17) [16].

Despite the GPHIN setback, it is evident that early during its first 100 cases, Canada's public health system was assembled and aware. A gradual federal stepwise response ensued (Table 1), and the Canadian Public Health Response Plan for Biological Events was heightened to Level Three—"Escalated."

However, despite the continuation of significant interprovincial air, train, road, and marine transportation and travel, a coordinated provincial/territorial response did not follow, and public health actions were initiated on different dates or not at all (Table 2).

Table 1. Early response to the COVID-19 pandemic by the federal government of Canada.

Date (2020)	Federal government interventions	China cases (new)	China deaths (new)	Global cases (new)	Global deaths (new)	Countries/territories/areas	Canada cases (new)	Canada deaths (new)	Canada tests (per million)
Jan 15	PHAC ^a activated Emergency Operations Centre	41	2 (1)	1	0	2	0	0	0
Jan 22	Screening for travelers returning from China	571 (131)	17 (11)	9	0	8	0	0	0
Feb 9	Screening for travelers returning from affected areas (10 airports, 6 provinces)	40,171 (2973)	908 (97)	382 (28)	2 (0)	26	7 (0)	0	346 (0.0000913)
Feb 27	Escalation to Level Three Response Level (Public Health Response Plan for biologic events)	78,824 (327)	2788 (44)	4228 (905)	70 (14)	53	14 (2)	0	1663 (0.000044)
Mar 13	Advised avoiding all nonessential travel outside of Canada	80,824 (11)	3189 (13)	64,592 (10,896)	2239 (434)	136	198 (56)	1 (0)	21,251 (0.00056)
Mar 16	Advised travelers entering Canada to self-isolate for 14 days	80,881 (21)	3226 (13)	101,533 (12,876)	3936 (629)	160	441 (100)	4 (3)	40,935 (0.0011)
Mar 18	Banned foreign nationals from all countries (except the United States); closed US-Canada border; redirected all international passenger flight arrivals to 4 airports; announced financial help	80,928 (34)	3245 (8)	137,816 (20 551)	5706 (964)	177	727 (129)	9 (1)	60,845 (0.0016)
Mar 25	Quarantine Act mandated all returning travelers to isolate themselves for 14 days	81,285 (67)	3287 (6)	389,750 (48,394)	17,995 (2382)	198	3409 (617)	36 (3)	138,700 (0.0037)

^aPHAC: Public Health Agency of Canada

Table 2. Early responses to the COVID-19 outbreak by provincial and territorial governments.

Action	Province or territory ^a												
	BC [17]	AB [18]	SK [19]	MB [20]	ON [21]	QC [22,23]	NB [24]	NS [25]	PE [26]	NL [27]	YT [28]	NT [29]	NU [30]
Self-isolation advised if returning from China	Feb 4	Feb 6	Feb 13	Feb 7	Feb 6	Feb 8	Feb 7	Feb 6	Feb 28	Feb 6	Feb 7	Mar 10	N/A ^b
Self-isolation advised if returning from a cruise	Feb 19	Mar 5	N/A	N/A	N/A	Mar 10	N/A	N/A	N/A	N/A	N/A	Mar 10	N/A
Self-monitoring of symptoms advised if traveled anywhere	Feb 24	Mar 6	Mar 11	Feb 27	Mar 10	Mar 11	Mar 1	Mar 9	Mar 9	Mar 6	Mar 13	Mar 14	Mar 4
Self-isolation advised if returning from Iran and China	Mar 3	Mar 2	Mar 5	Mar 5	Mar 3	Mar 3	Mar 9	Mar 13	N/A	N/A	Mar 13	Mar 10	N/A
Self-isolation advised if returning from Italy	N/A	Mar 12	Mar 9	Mar 12	Mar 13	Mar 10	Mar 11 (health care workers only)	Mar 13	N/A	N/A	Mar 13	Mar 14	N/A
Self-isolation advised if returning from outside of Canada	Mar 12	Mar 12	Mar 14	Mar 15	Mar 14	Mar 12	Mar 19	Mar 15	Mar 13	Mar 14	Mar 16	Mar 15	Mar 15 (announced Mar 18)
Screening event participants (symptoms, international travelers)	Mar 3	Mar 10	Mar 16	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
Social distancing recommended	Mar 7	Mar 13	Mar 11	Mar 12	Mar 15	Mar 12	Mar 12	Mar 13	Mar 13	Mar 13	Mar 16	Mar 17	Mar 13
Testing announced for travelers to at-risk areas and for local transmission	Jan 21	Feb 26	Feb 13	Jan 28	Jan 24	Jan 22	Feb 10	Feb 6	Feb 28	Feb 6	Jan 14	Feb 5	N/A

Action	Province or territory ^a												
	BC [17]	AB [18]	SK [19]	MB [20]	ON [21]	QC [22,23]	NB [24]	NS [25]	PE [26]	NL [27]	YT [28]	NT [29]	NU [30]
Testing expanded to any international traveler with symptoms and contacts	Feb 25	Mar 6	Mar 11	Feb 27	Feb 28	Mar 8	Mar 1	Mar 9	Mar 9	Mar 6	Mar 16	Mar 14	N/A
All respiratory specimens tested for COVID-19	N/A	Mar 12	NA	Mar 12	Mar 5	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
First testing center(s) opened	Mar 13	Mar 15	Mar 13	Mar 12	Mar 13	Mar 9	Mar 16	Mar 11	Mar 11	Mar 21	Mar 26	Mar 23 (drive-through)	N/A

^aAbbreviations: BC: British Columbia; AB: Alberta; SK: Saskatchewan; MB: Manitoba; ON: Ontario; QC: Quebec; NB: New Brunswick; NS: Nova Scotia; PE: Prince Edward Island; NL: Newfoundland and Labrador; YT: Yukon Territory; NT: Northwest Territories; NU: Nunavut.

^bN/A: not applicable.

Pandemic Disease Surveillance

The WHO recommends a comprehensive assessment of the earliest cases, with documentation of geographical spread, trends, and impact, to better inform public health response [3]. Canada prioritized the protection of individuals' privacy, collected volunteered data, and relied on coordination between national and provincial or territorial departments [7]. On February 10, PHAC provided interim surveillance guidelines with COVID-19 case definitions to guide provincial/territorial legislation, regulations, and policies [31]. This included reporting cases nationally to PHAC within 24 hours of notification, provincial/territorial case interviews to identify close contacts, and monitoring health status. Identified close contacts were categorized based on risk exposure, with high risks requiring intermittent public health monitoring only.

During the first 100 cases, concluding on March 10, Canada performed approximately 11,023 tests, with significant variation between provinces and territories. The tests were initially processed at Canada's national laboratory in Winnipeg, an inefficient process that led to delayed reporting. By February 25, only provincial laboratories in Ontario and British Columbia were ready to perform independent testing; however, routine COVID-19 testing for respiratory specimens was not implemented until later. The Canadian Broadcasting Corporation reported on testing variations and noted provincial/territorial differences in rates of testing, groups that were "targeted," and frequent changes to policies [32]. Together, these actions led to large exclusions of asymptomatic and even symptomatic patients outside the "targeted" groups [32].

Buoyed by lessons learned from previous pandemics, South Korea launched an expansive and organized surveillance program that could objectively verify contact investigations. Recognizing that interviews would result in omitted or erroneous

information, the importance of evaluating between-person risk and the elimination of infection exposure in contaminated places were prioritized. Interviews, medical facility records, credit card transactions, closed-circuit television and medical facility records were used to determine case locations, evaluate exposure risk, and classify contacts [33]. Social media apps were employed that informed users of potential contact with infected persons. During the first 100 cases in South Korea, 13,302 tests were conducted over a 30-day period [34]. Commercial test kits were rapidly developed, and drive-through screening centers were created early in the outbreak. This enabled increased testing capacity and prevention of cross-infection of testees by eliminating public waiting spaces [35].

South Korea's techno-driven approach enabled a wider spectrum of societal surveillance and the capturing of cases well beyond the capacity of Canada's human-driven approach, which focused on interviewing and testing hospitalized patients, health care workers, residents in long-term care facilities, or other "clusters." Interestingly, although the approaches were somewhat polarizing regarding individual privacy versus public safety priorities, as the COVID-19 pandemic progressed in Canada, discussions around implementing techno-driven measures began to intensify.

Reducing the Spread of COVID-19

Individual- and Household-Level Measures

Individual- and household-level measures minimize interactions within and outside the home at the onset of symptoms [3]. During Canada's first 100 cases, self-isolation was mainly recommended for positive cases, close contacts, and people returning from high-risk travel regions. Later, as the number of COVID-19 cases increased, an Emergency Order under Canada's Quarantine Act legally mandated self-isolation after

international travel, with violators facing significant financial penalties and/or imprisonment.

In contrast, Singapore's experience of rapidly containing the SARS outbreak led to the quarantine of 425 close contacts at home or designated government facilities after only 36 cases from 3 clusters were identified [36]. "Close contacts" were identified as individuals who had spent a prolonged period of time within 2 meters of a confirmed case. "Other contacts," or individuals who had some interactions with confirmed cases, were also followed. The health status and location of the contacts were routinely monitored via videoconferencing or telephone surveillance, clear directives were provided in the event that an individual became unwell, and quarantine violators were tagged with continuous tracking devices. These actions were deemed necessary to document early community transmission and facilitate containment efforts [36].

Societal-Level Measures

Societal-level measures include social distancing with a focus on school suspensions, working pattern adjustments, reduction of crowding on public transportation, and cancellation, modification, or restriction of mass gatherings [3]. Only two provinces recommended social distancing during Canada's first 100 cases; all the aforementioned social level measures were employed later.

In contrast, Hong Kong's experience with SARS demonstrated the importance of early community measures to reduce population contacts [37]. Within days of the first reported case in Hong Kong, theme parks were closed, cross-border bus services were suspended, school reopening was postponed, and civil servants adopted flexible working arrangements, including work-from-home options [38]. These restrictions, together with other nonpharmaceutical interventions, were associated with reduced COVID-19 transmission [38].

International Travel Measures

International travel measures have been very contentious during the pandemic, as the WHO recommended implementing exit screens and providing advice to travelers [3] but did not recommend border closures. The Canadian government did create a basic contact information form with the Canadian Border Security Agency; however, 31 of 2226 travelers from Hubei Province were referred to PHAC, and of these, only 3 were medically examined [39]. Travelers from affected areas were also screened (Table 1), although more than half of infected people would be undetectable and missed because of unknown exposure or lack of symptoms [40]. Self-isolation after travel was also advised by most provinces and territories in an incremental fashion; however, sizable discrepancies in initiation dates can be noted (Table 2). On February 27, an open letter from 23 Chinese-Canadian doctors urged for the implementation of stronger measures that included a 14-day quarantine for travelers returning from COVID-19 hotspots [41]. These measures, including escalation to closed international borders and restricted domestic travel, would be realized well after the first 100 cases were reported.

In contrast, Taiwan's national command center, a response to the SARS outbreak, rapidly implemented border control

measures [42]. Passengers completed a health questionnaire upon arrival, and by integrating big data from national health and immigration registries, officials were able to quickly classify infectious risk status based on flight origin and travel history [42]. Travelers with minimal risks received a mobile pass that facilitated faster immigration clearance, while others identified as high risk were screened for 26 viruses, placed in home quarantine, and monitored electronically for compliance [42]. Further actions, including flight and visitor visa restrictions, would ensue; however, these actions were secondary in importance to Taiwan's early border response, which began on the day China disclosed its first case.

Continuity and Provision of Health Care

Infection Control and Personal Protective Equipment

According to the WHO, enhancing infection control practices and distributing personal protective equipment (PPE) are important actions during an early pandemic response [3]. During the first 100 cases, PHAC evaluated domestic supplies of PPE and began to conserve and coordinate supplies due to mounting market pressures [39]. Only later, after PHAC recognized that their stockpile was not adequate, were Canadian companies asked to adjust their production lines to begin manufacturing PPE.

In contrast, Taiwan actively bolstered the provision of medical supplies very early in the pandemic. Specifically for PPE, authorities halted their exports, acquired assembly lines to boost domestic production, mobilized military personnel to assist manufacturers, and established a central distribution system. Using a cloud computing system, Taiwan also developed a rationing system based on national health insurance data [43] to prevent hoarding of PPE. This was no small task. To ensure that the new application would not overwhelm the cloud, in which medical records were normally stored, 20 new servers were set up by engineers in one day.

Mobilizing the Health Care System

Pandemic contingency plans that mobilize health systems, facilities, and workers [3] may be more complicated in countries such as Canada, where the federal government has limited authority in the management, delivery, and organization of services. The federal PHAC did trigger a provincial and territorial public health response plan. However, during the first 100 cases, a patchwork of decentralized provincial and territorial responses resulted rather than quick, decisive, and cohesive actions that could have mitigated risk [44].

In contrast, Singapore's Ministry of Health coordinated their COVID-19 activities through centralized systems. At the onset of their response, they activated a crisis system that enabled daily text messaging to the country, provided two-way communication channels with hospital executives, epidemiologists, and operational workgroups, and facilitated cross-hospital information sharing [45]. Their hospital systems were prepared through routine mass infectious crisis simulations that involved staff at every level [45].

Communications

Finally, communications with the public regarding disruptions, sources, and resources for medical needs as well as COVID-19 itself [3] were conducted largely by PHAC and provincial and territorial authorities. Early in the pandemic, press conferences often lacked clarity, problems of uniform messaging between provinces and the federal government were noted, and releases of aggregate case statistics were inconsistent in timing and details [46]. When questioned whether the federal government should take a more proactive role in messaging and publishing data, Deputy Prime Minister Chrystia Freeland responded that “Canada is not a highly centralized country” [46].

Singapore recognized social media’s contribution to information flow during the SARS epidemic through its volume of use and the ease of creating false narratives [47]. Since the first case was reported in Singapore, the government has provided daily updates on traditional platforms such as print media, broadcasts, town hall meetings, and, more importantly, websites and social media (eg, WhatsApp, Twitter, Facebook, Telegram) [47]. Due to its high penetration, the WhatsApp social media platform was upgraded with artificial intelligence translation, easy signup, fast updates, and end-to-end data encryption to manage its increased demand and the need to rapidly deploy information.

Beyond the First 100 Cases

As the pandemic progressed beyond the first 100 cases, Canadian officials began to look towards more “techno-driven” approaches to control the spread of COVID-19. For example, one app named “COVID Alert” was developed to inform citizens of possible exposures [48]; however, although the app protected users’ privacy, its adoption was not widespread. Testing became more streamlined, with many jurisdictions providing drive-through facilities. International and provincial borders

were closed, PPE production and supplies were bolstered, and societal measures were amplified. Canada’s later actions mimicked the very early interventions from southeast Asian countries but continued to be largely uncoordinated between provincial entities.

Implications

Canada’s early decentralized “human-driven” approach resulted in inefficient testing, suboptimal disease containment, and an inadequately mobilized health care system. These observations have also been noted in other Western democracies that value protection of individuals’ privacy, consensus building, and information sharing [7]. A coordinated “techno-driven” approach offers several pragmatic advantages; however, concerns about freedom and individuals’ rights must be considered. For future pandemics, the challenge may be to intentionally develop “techno-driven” approaches to assist with coordinated national responses while protecting individuals’ privacies and freedoms.

Conclusions

Canada’s response to the COVID-19 outbreak during its first 100 cases could be characterized as decentralized, uncoordinated, slow, and “human-driven.” In contrast, a number of southeast Asian nations and jurisdictions that had wrestled with significant and recent pandemics demonstrated early responses that were centralized, coordinated, rapid, comprehensive, and “techno-driven.” Although these regions shared borders with China, received high volumes of travelers from Wuhan, and became involved in the pandemic very early, their mortality rates were miniscule compared to that in Canada. To optimize future action, an early coordinated approach that is “techno-driven” could be considered by Canadian public health officials.

Conflicts of Interest

None declared.

References

1. Rolling updates on coronavirus disease (COVID-19). World Health Organization. URL: <https://www.who.int/emergencies/diseases/novel-coronavirus-2019/events-as-they-happen> [accessed 2020-04-15]
2. Whole-of-Society Pandemic Readiness: WHO guidelines for pandemic preparedness and response in the non-health sector. World Health Organization. 2009. URL: https://www.who.int/influenza/preparedness/pandemic/2009-0808_wos_pandemic_readiness_final.pdf?ua=1 [accessed 2020-04-01]
3. Pandemic Influenza Preparedness and response: Phases 5-6 Pandemic. World Health Organization. 2009. URL: https://www.who.int/influenza/resources/documents/extract_PIPGuidance09_phase5_6.pdf?ua=1 [accessed 2020-04-01]
4. McCaw JM, Glass K, Mercer GN, McVernon J. Pandemic controllability: a concept to guide a proportionate and flexible operational response to future influenza pandemics. *J Public Health (Oxf)* 2014 Mar;36(1):5-12 [FREE Full text] [doi: [10.1093/pubmed/fdt058](https://doi.org/10.1093/pubmed/fdt058)] [Medline: [23735960](https://pubmed.ncbi.nlm.nih.gov/23735960/)]
5. Black AJ, Geard N, McCaw JM, McVernon J, Ross JV. Characterising pandemic severity and transmissibility from data collected during first few hundred studies. *Epidemics* 2017 Jun;19:61-73 [FREE Full text] [doi: [10.1016/j.epidem.2017.01.004](https://doi.org/10.1016/j.epidem.2017.01.004)] [Medline: [28189386](https://pubmed.ncbi.nlm.nih.gov/28189386/)]
6. Epidemiological summary of COVID-19 cases in Canada. Government of Canada. URL: <https://www.canada.ca/en/public-health/services/diseases/2019-novel-coronavirus-infection/health-professionals/epidemiological-summary-covid-19-cases.html> [accessed 2020-04-01]

7. Kummitha RKR. Smart technologies for fighting pandemics: The techno- and human- driven approaches in controlling the virus transmission. *Gov Inf Q* 2020 Jul;37(3):101481 [FREE Full text] [doi: [10.1016/j.giq.2020.101481](https://doi.org/10.1016/j.giq.2020.101481)] [Medline: [32313361](https://pubmed.ncbi.nlm.nih.gov/32313361/)]
8. Carter D, Stojanovic M, De Bruijn B. Revitalizing the Global Public Health Intelligence Network (GPHIN). *OJPHI* 2018 May 22;10(1). [doi: [10.5210/ojphi.v10i1.8912](https://doi.org/10.5210/ojphi.v10i1.8912)]
9. Brewster M. Inside Canada's frayed pandemic early warning system and its COVID-19 response: The Global Public Health Intelligence Network was getting an overdue tech upgrade when COVID-19 hit. *CBC News*. URL: <https://www.cbc.ca/news/politics/covid19-pandemic-early-warning-1.5537925> [accessed 2020-05-01]
10. McCall B. COVID-19 and artificial intelligence: protecting health-care workers and curbing the spread. *Lancet Digit Health* 2020 Apr;2(4):e166-e167 [FREE Full text] [doi: [10.1016/S2589-7500\(20\)30054-6](https://doi.org/10.1016/S2589-7500(20)30054-6)] [Medline: [32289116](https://pubmed.ncbi.nlm.nih.gov/32289116/)]
11. Government of Canada takes action on COVID-19. Government of Canada. URL: <https://www.canada.ca/en/public-health/services/diseases/2019-novel-coronavirus-infection/canadas-reponse/government-canada-takes-action-covid-19.html> [accessed 2020-04-20]
12. Federal/Provincial/Territorial Public Health Response Plan for Biological Events. Government of Canada. 2017 Oct 31. URL: <https://www.canada.ca/en/public-health/services/emergency-preparedness/public-health-response-plan-biological-events.html> [accessed 2020-04-01]
13. Bai Y, Yao L, Wei T, Tian F, Jin D, Chen L, et al. Presumed Asymptomatic Carrier Transmission of COVID-19. *JAMA* 2020 Apr 14;323(14):1406-1407 [FREE Full text] [doi: [10.1001/jama.2020.2565](https://doi.org/10.1001/jama.2020.2565)] [Medline: [32083643](https://pubmed.ncbi.nlm.nih.gov/32083643/)]
14. Read J, Bridgen J, Cummings D, Ho A, Jewell C. Novel coronavirus 2019-nCoV: early estimation of epidemiological parameters and epidemic predictions. medRxiv. Preprint posted online on January 28, 2020 2020. [doi: [10.1101/2020.01.23.20018549](https://doi.org/10.1101/2020.01.23.20018549)]
15. Zafar T. Novel Coronavirus (NCOV-2019): A Global Health Emergency. *JAMDC* 2019 Dec;01(04):127-128 [FREE Full text] [doi: [10.51127/jamdcv1i4editorial01](https://doi.org/10.51127/jamdcv1i4editorial01)]
16. Linton NM, Kobayashi T, Yang Y, Hayashi K, Akhmetzhanov AR, Jung S, et al. Incubation Period and Other Epidemiological Characteristics of 2019 Novel Coronavirus Infections with Right Truncation: A Statistical Analysis of Publicly Available Case Data. *J Clin Med* 2020 Feb 17;9(2) [FREE Full text] [doi: [10.3390/jcm9020538](https://doi.org/10.3390/jcm9020538)] [Medline: [32079150](https://pubmed.ncbi.nlm.nih.gov/32079150/)]
17. COVID-19. BC Centre for Disease Control. URL: <http://www.bccdc.ca/health-info/diseases-conditions/covid-19> [accessed 2020-04-15]
18. COVID-19 Info for Albertans. Government of Alberta. URL: <https://www.alberta.ca/coronavirus-info-for-albertans.aspx> [accessed 2020-04-25]
19. Novel Coronavirus (COVID-19). Government of Saskatchewan. URL: <https://www.saskatchewan.ca/government/health-care-administration-and-provider-resources/treatment-procedures-and-guidelines/emerging-public-health-issues/2019-novel-coronavirus> [accessed 2020-04-15]
20. COVID-19 Novel Coronavirus. Government of Manitoba. URL: <https://manitoba.ca/covid19/> [accessed 2020-04-15]
21. COVID-19. Government of Ontario. URL: <https://covid-19.ontario.ca> [accessed 2020-04-01]
22. Situation of the Coronavirus (COVID-19) in Quebec. Government of Quebec. URL: <https://www.quebec.ca/en/health/health-issues/a-z/2019-coronavirus/situation-coronavirus-in-quebec/> [accessed 2020-04-01]
23. Coronavirus (COVID-19). Ministère de la Santé et des Services Sociaux (MSSS) Québec. Webpage in French. URL: <https://msss.gouv.qc.ca/professionnels/maladies-infectieuses/coronavirus-2019-ncov/> [accessed 2020-04-01]
24. Office of the Chief Medical Officer of Health (Public Health): Coronavirus. Government of New Brunswick. URL: https://www2.gnb.ca/content/gnb/en/departments/ocmoh/cdc/content/respiratory_diseases/coronavirus.html [accessed 2020-04-01]
25. Novel Coronavirus (COVID-19): Government's Response to Covid-19. Government of Nova Scotia. URL: <https://novascotia.ca/coronavirus/> [accessed 2020-04-01]
26. COVID-19. Government of Prince Edward Island. URL: <https://www.princeedwardisland.ca/en/topic/covid-19> [accessed 2020-04-01]
27. COVID-19. Government of Newfoundland and Labrador. URL: <https://www.gov.nl.ca/covid-19/> [accessed 2020-04-01]
28. Information about COVID-19. Government of Yukon. URL: <https://yukon.ca/covid-19> [accessed 2020-04-01]
29. Health and Social Services: Coronavirus Disease (COVID-19). Government of Northwest Territories. URL: <https://www.hss.gov.nt.ca/en/services/coronavirus-disease-covid-19> [accessed 2020-04-15]
30. Tahirali J, Singh M, Ho S, Slaughter G. Coronavirus: Tracking Every Case of COVID-19 in Canada. *CTV News*. 2020 Mar 13. URL: <https://www.ctvnews.ca/health/coronavirus/tracking-every-case-of-covid-19-in-canada-1.4852102> [accessed 2020-04-28]
31. Interim national surveillance guidelines for human infection with Coronavirus disease (COVID-19). Government of Canada. URL: <https://www.canada.ca/en/public-health/services/diseases/2019-novel-coronavirus-infection/health-professionals/interim-guidance-surveillance-human-infection.html> [accessed 2020-03-25]
32. Chung E. Why COVID-19 testing varies so much across Canada. *CBC news*. URL: <https://www.cbc.ca/news/health/covid-19-testing-variations-1.5520812> [accessed 2020-04-25]
33. Cumulative number of coronavirus (COVID-19) tests conducted in South Korea from January 23 to April 11, 2020. *Statista*. 2020 May. URL: <https://www.statista.com/statistics/1102818/south-korea-covid-19-test-total-number/> [accessed 2020-05-10]

34. Hasell J, Ortiz-Ospina E, Mathieu E, Richie H, Beltekian D, McDonald B, et al. Coronavirus (COVID-19) Testing. Our World in Data. URL: <https://ourworldindata.org/covid-testing> [accessed 2020-05-01]
35. Kwon KT, Ko JH, Shin H, Sung M, Kim JY. Drive-Through Screening Center for COVID-19: a Safe and Efficient Screening System against Massive Community Outbreak. *J Korean Med Sci* 2020 Mar 23;35(11):e123 [FREE Full text] [doi: [10.3346/jkms.2020.35.e123](https://doi.org/10.3346/jkms.2020.35.e123)] [Medline: [32193904](https://pubmed.ncbi.nlm.nih.gov/32193904/)]
36. Pung R, Chiew CJ, Young BE, Chin S, Chen MI, Clapham HE, Singapore 2019 Novel Coronavirus Outbreak Research Team. Investigation of three clusters of COVID-19 in Singapore: implications for surveillance and response measures. *Lancet* 2020 Mar 28;395(10229):1039-1046 [FREE Full text] [doi: [10.1016/S0140-6736\(20\)30528-6](https://doi.org/10.1016/S0140-6736(20)30528-6)] [Medline: [32192580](https://pubmed.ncbi.nlm.nih.gov/32192580/)]
37. Lau JTF, Yang X, Tsui H, Kim JH. Monitoring community responses to the SARS epidemic in Hong Kong: from day 10 to day 62. *J Epidemiol Community Health* 2003 Nov;57(11):864-870 [FREE Full text] [doi: [10.1136/jech.57.11.864](https://doi.org/10.1136/jech.57.11.864)] [Medline: [14600111](https://pubmed.ncbi.nlm.nih.gov/14600111/)]
38. Cowling BJ, Ali ST, Ng TWY, Tsang TK, Li JCM, Fong MW, et al. Impact assessment of non-pharmaceutical interventions against coronavirus disease 2019 and influenza in Hong Kong: an observational study. *Lancet Public Health* 2020 May;5(5):e279-e288 [FREE Full text] [doi: [10.1016/S2468-2667\(20\)30090-6](https://doi.org/10.1016/S2468-2667(20)30090-6)] [Medline: [32311320](https://pubmed.ncbi.nlm.nih.gov/32311320/)]
39. Aiello R. Documents reveal glimpse into Canada's early COVID-19 plans. CTV News. URL: <https://www.ctvnews.ca/health/coronavirus/documents-reveal-glimpse-into-canada-s-early-covid-19-plans-1.4886560> [accessed 2020-04-20]
40. Gostic K, Gomez AC, Mummah RO, Kucharski AJ, Lloyd-Smith JO. Estimated effectiveness of symptom and risk screening to prevent the spread of COVID-19. *eLife* 2020 Feb 24;9 [FREE Full text] [doi: [10.7554/eLife.55570](https://doi.org/10.7554/eLife.55570)] [Medline: [32091395](https://pubmed.ncbi.nlm.nih.gov/32091395/)]
41. Blackwell T. ?Nothing to do with discrimination?: Chinese-Canadian MDs urge everyone returning from China to self-quarantine. *National Post*. URL: <https://nationalpost.com/news/toronto-area-doctors-urge-all-travellers-from-china-to-voluntarily-enter-two-week-quarantine> [accessed 2020-03-25]
42. Wang CJ, Ng CY, Brook RH. Response to COVID-19 in Taiwan: Big Data Analytics, New Technology, and Proactive Testing. *JAMA* 2020 Apr 14;323(14):1341-1342. [doi: [10.1001/jama.2020.3151](https://doi.org/10.1001/jama.2020.3151)] [Medline: [32125371](https://pubmed.ncbi.nlm.nih.gov/32125371/)]
43. Ngerng R. Taiwan's digital response to Covid-19: impressive, but is privacy respected? *The News Lens*. 2020 Mar 27. URL: <https://international.thenewslens.com/article/133095> [accessed 2020-04-20]
44. Tomlinson K, Roberston G. Ottawa had a playbook for a coronavirus-like pandemic 14 years ago. What went wrong? *The Globe and Mail*. 2020 Apr 09. URL: <https://www.theglobeandmail.com/canada/article-ottawa-had-a-playbook-for-a-coronavirus-like-pandemic-14-years-ago/> [accessed 2020-04-20]
45. Vidyarthi AR, Bagdasarian N, Esmaili AM, Archuleta S, Monash B, Sehgal NL, et al. Understanding the Singapore COVID-19 Experience: Implications for Hospital Medicine. *J Hosp Med* 2020 May;15(5):281-283. [doi: [10.12788/jhm.3436](https://doi.org/10.12788/jhm.3436)] [Medline: [32379029](https://pubmed.ncbi.nlm.nih.gov/32379029/)]
46. Ling J. Where Canada is falling short on its coronavirus communications. *Maclean's*. 2020 Mar 19. URL: <https://www.macleans.ca/news/canada/canadas-mixed-messages-on-the-coronavirus-outbreak/> [accessed 2020-04-10]
47. Wong JEL, Leo YS, Tan CC. COVID-19 in Singapore-Current Experience: Critical Global Issues That Require Attention and Action. *JAMA* 2020 Apr 07;323(13):1243-1244. [doi: [10.1001/jama.2020.2467](https://doi.org/10.1001/jama.2020.2467)] [Medline: [32077901](https://pubmed.ncbi.nlm.nih.gov/32077901/)]
48. Download COVID Alert today. Government of Canada. URL: <https://www.canada.ca/en/public-health/services/diseases/coronavirus-disease-covid-19/covid-alert.html#a2> [accessed 2020-09-17]

Abbreviations

GPHIN: Global Public Health Intelligence Network

PHAC: Public Health Agency of Canada

PPE: Personal Protective Equipment

SARS: severe acute respiratory syndrome

WHO: World Health Organization

Edited by G Eysenbach, R Kukafka; submitted 17.05.20; peer-reviewed by R Kummitha, Q Liao; comments to author 13.07.20; revised version received 17.08.20; accepted 12.12.20; published 23.12.20.

Please cite as:

Hansen G, Cyr A

Canada's Decentralized "Human-Driven" Approach During the Early COVID-19 Pandemic

JMIR Public Health Surveill 2020;6(4):e20343

URL: <http://publichealth.jmir.org/2020/4/e20343/>

doi: [10.2196/20343](https://doi.org/10.2196/20343)

PMID: [33315582](https://pubmed.ncbi.nlm.nih.gov/33315582/)

©Gregory Hansen, Amelie Cyr. Originally published in JMIR Public Health and Surveillance (<http://publichealth.jmir.org>), 23.12.2020. This is an open-access article distributed under the terms of the Creative Commons Attribution License (<https://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in JMIR Public Health and Surveillance, is properly cited. The complete bibliographic information, a link to the original publication on <http://publichealth.jmir.org>, as well as this copyright and license information must be included.

Original Paper

Public Health Interventions' Effect on Hospital Use in Patients With COVID-19: Comparative Study

Xiaofeng Wang^{1*}, PhD; Rui Ren^{2*}, BSc; Michael W Kattan¹, PhD; Lara Jehi³, MD; Zhenshun Cheng⁴, MD; Kuangnan Fang^{2*}, PhD

¹Department of Quantitative Health Sciences, Cleveland Clinic, Cleveland, OH, United States

²Department of Statistics, Xiamen University, Xiamen, China

³Neurological Institute, Cleveland Clinic, Cleveland, OH, United States

⁴Department of Pulmonary and Critical Care Medicine, Zhongnan Hospital of Wuhan University, Wuhan, China

*these authors contributed equally

Corresponding Author:

Xiaofeng Wang, PhD

Department of Quantitative Health Sciences

Cleveland Clinic

9500 Euclid Avenue

Cleveland, OH, 44195

United States

Phone: 1 216 445 7737

Email: wangx6@ccf.org

Abstract

Background: Different states in the United States had different nonpharmaceutical public health interventions during the COVID-19 pandemic. The effects of those interventions on hospital use have not been systematically evaluated. The investigation could provide data-driven evidence to potentially improve the implementation of public health interventions in the future.

Objective: We aim to study two representative areas in the United States and one area in China (New York State, Ohio State, and Hubei Province), and investigate the effects of their public health interventions by time periods according to key interventions.

Methods: This observational study evaluated the numbers of infected, hospitalized, and death cases in New York and Ohio from March 16 through September 14, 2020, and Hubei from January 26 to March 31, 2020. We developed novel Bayesian generalized compartmental models. The clinical stages of COVID-19 were stratified in the models, and the effects of public health interventions were modeled through piecewise exponential functions. Time-dependent transmission rates and effective reproduction numbers were estimated. The associations of interventions and the numbers of required hospital and intensive care unit beds were studied.

Results: The interventions of social distancing, home confinement, and wearing masks significantly decreased (in a Bayesian sense) the case incidence and reduced the demand for beds in all areas. Ohio's transmission rates declined before the state's "stay at home" order, which provided evidence that early intervention is important. Wearing masks was significantly associated with reducing the transmission rates after reopening, when comparing New York and Ohio. The centralized quarantine intervention in Hubei played a significant role in further preventing and controlling the disease in that area. The estimated rates that cured patients become susceptible in all areas were small (<0.0001), which indicates that they have little chance to get the infection again.

Conclusions: The series of public health interventions in three areas were temporally associated with the burden of COVID-19-attributed hospital use. Social distancing and the use of face masks should continue to prevent the next peak of the pandemic.

(*JMIR Public Health Surveill* 2020;6(4):e25174) doi:[10.2196/25174](https://doi.org/10.2196/25174)

KEYWORDS

COVID-19; public health; intervention; hospital; use; prediction; comparative; United States; China; implementation; observational

Introduction

A novel coronavirus was identified as the cause of a cluster of pneumonia cases in Wuhan, the capital city of Hubei Province, China, at the end of 2019. It quickly spread throughout China, followed by an increasing number of cases in other countries. The virus was named SARS-CoV-2. The World Health Organization (WHO) designated the disease caused by SARS-CoV-2 as COVID-19. The disease's main clinical manifestations include fever, cough, shortness of breath, fatigue, and dyspnea [1-4], with progression to multi-organ dysfunction in severe cases. In March 2020, the WHO declared the COVID-19 outbreak a global pandemic. As of October 20, 2020, there are 40,756,188 cases (including 1,124,627 deaths) attributed to COVID-19 that have been reported worldwide, with sustained transmission in many countries, including the United States.

Many statistical and mathematical models were proposed to estimate the dynamics and the potential spread of COVID-19 [5-9]. The classical compartmental models such as the susceptible-exposed-infectious-removed (SEIR) models were the most widely used [10]. These models were applied to estimate the transmission risks, predict the numbers of infected subjects, and evaluate the public health interventions [9,11,12]. A key parameter in these models was the basic reproduction number (R_0), defined as the expected number of additional cases that one case will generate. If R_0 is above 1, continuous human-to-human transmission with sustained transmission chains will occur. The median R_0 of COVID-19 was recently estimated [12] at 2.79 (IQR 1.16), which is significantly higher than that of the severe acute respiratory syndrome coronavirus.

Admissions to hospitals and intensive care units (ICUs) increased exponentially during the first few weeks of the outbreak in many countries, significantly straining resources and, at times, transforming a public health emergency into an operational crisis [13]. Rigorous government control policies were instituted to slow the spread of the disease and reduce the burden of COVID-19-attributed hospital use. Although associations of public health interventions with COVID-19 epidemiology in Wuhan City were studied [14,15], the effects of these interventions on hospital use at a state level remain to be investigated. This knowledge gap is significant given the growing public health concern regarding the adequacy of resources to treat severe COVID-19, including hospital beds, ICUs, and ventilators, in the United States. To project the timing of the outbreak peak and the number of ICU beds required at the peak, Moghadas et al [11] simulated a COVID-19 outbreak parameterized with the US population demographics. Grasselli et al [16] presented a linear model as well as an exponential model to predict ICU admissions.

However, most of the current models used prespecified parameters from the literature to simulate the COVID-19 outbreak [17]. They did not account for dynamic disease evolution, which often resulted in underestimating or overestimating hospital use. In this study, we propose a novel generalized dynamic SEIR model. The clinical stages of COVID-19 are stratified in the model, and the effects of public

health interventions are modeled through piecewise exponential functions. Unlike the other existing methods, we estimated all dynamic parameters from observed epidemic data through Bayesian inferences.

In the United States, New York State was hit the hardest by COVID-19 in the early stage of the pandemic, and Ohio State had early public health interventions by its government and medical community. In China, Hubei Province was where COVID-19 was first detected, and the province was put under strict lockdown. Using the proposed model, we aim to evaluate and compare the effectiveness of public health interventions on hospital use in patients with COVID-19 for the three representative areas; in addition, we aim to study the time-dependent associations between the interventions and transmission rates and effective reproduction numbers.

Methods

Data Sources

The epidemiological data of COVID-19 in New York State and Ohio State were obtained from the Centers for Disease Control and Prevention of the United States, Johns Hopkins Coronavirus Resource Center [18], and the COVID tracking project from the Atlantic [19]. We collected the daily number of confirmed cases, the number of cumulative deaths, and the number of cumulative cured cases from March 12 to September 14, 2020. In addition, we obtained the number of hospitalization cases from March 21 to September 14, 2020, in New York and the numbers of hospitalized, mild, severe, and critically ill patients in Ohio from May 2 to September 14. In this study, the data from March 12 to August 31 were used for model building, and the data from September 1 to September 14 were used for external validation.

The epidemiological data of COVID-19 in Hubei, China were mainly obtained from the National Health Commission of China, Chinese Center for Disease Control and Prevention, and Hubei Provincial Health Commission [20]. We collected the daily numbers of confirmed infected cases, cured cases, and deaths from December 1, 2019, to March 31, 2020. We also extracted the numbers of hospitalized, mild, severe, and critically ill patients from January 26 to March 31, 2020.

Dynamic SEIR Model

In the classical SEIR model, the human-to-human transmission of COVID-19 was modeled using a compartmental representation of the disease where an individual occupied one of the four states: susceptible (S), exposed (E), infectious (I), and removed (R). The population was assumed to have a homogeneous spatial distribution. Susceptible individuals could acquire the virus through contact with individuals in the infectious compartment and become exposed. The exposed individuals were infected but not yet infectious. They experienced an incubation duration and progress to the infectious stage at a certain rate. The infectious individuals could progress into the removed stage (usually recovered with immunity) at another rate.

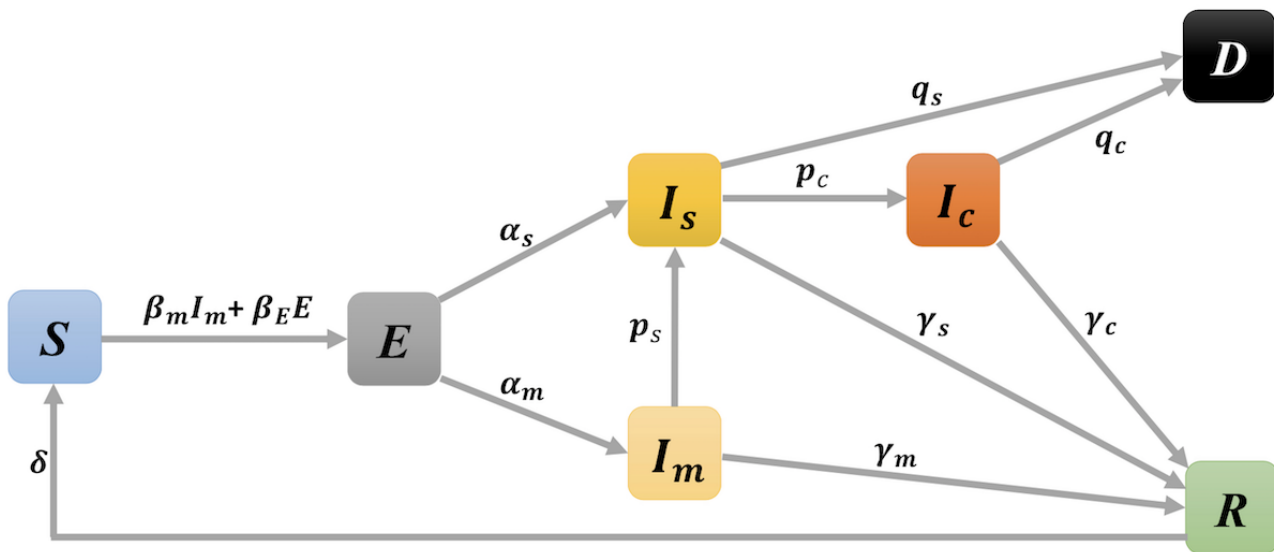
To characterize the hospital use for patients with COVID-19, we generalized the classical SEIR model by introducing a few

new compartments. We considered three clinical stages for COVID-19 in our model [4,21]: mild, severe, and critical. Mild included patients who had symptoms like fever and cough, and may have mild pneumonia. Hospitalization was not required in the United States, but such individuals were required to admit to temporary hospitals in China. Severe was characterized by dyspnea, respiratory frequency ≥ 30 /minute, blood oxygen saturation $\leq 93\%$, PaO₂/FiO₂ ratio < 300 , or lung infiltrates $> 50\%$ within 24-48 hours. Hospitalization and supplemental oxygen were generally required for them. Critical cases exhibited respiratory failure, septic shock, or multiple organ dysfunction

and failure. Treatment in an ICU, often with mechanical ventilation, was typically required.

Figure 1 displays the flowchart of the proposed model. Here, the infectious stage includes all individuals who are confirmed COVID-19 cases, which is composed of three subcompartments: I_m represents the infectious individuals with mild symptoms, I_s represents the severe patients, and I_c represents the patients who were critically ill. The removed stage includes two subcompartments: the dead compartment (D) and the recovered compartment (R).

Figure 1. Flowchart of the dynamic susceptible-exposed-infectious-removed model.



We assumed that an individual who is susceptible or at risk can only be infected by exposed individuals (patients with COVID-19 who had not been confirmed) or mild patients, since severe or critically ill patients were hospitalized and had a small (ignorable) probability to infect others. In Figure 1, β_m is the transmission rate that infectious individuals in the compartment I_m contact susceptibles and infect them, and β_E is the transmission rate at which exposed individuals in E contact susceptibles and infect them. α_* is the rate of progression from the exposed to infectious class I_* , where the subscript “*” denotes one of the patient groups, mild (m), severe (s), and critically ill (c). γ_* is the rate that infectious individuals in class I_* recover from the disease. p_s is the rate that infectious individuals in I_m progress to I_s , and p_c is the rate that infectious individuals in I_s progress to I_c . q represents the death rate for patients who are critically ill. Since the WHO recently stated that there was no evidence that patients who recover from COVID-19 are entirely immune, we used δ to represent the rate that infected individuals are cured and become susceptible again. The mathematical details of the proposed model are given in Multimedia Appendix 1.

Mathematically, our model is expressed as a system of ordinary differential equations:



with the size of population N :

$$N = S(t) + E(t) + I_m(t) + I_s(t) + I_c(t) + R(t) + D(t) \quad (8)$$

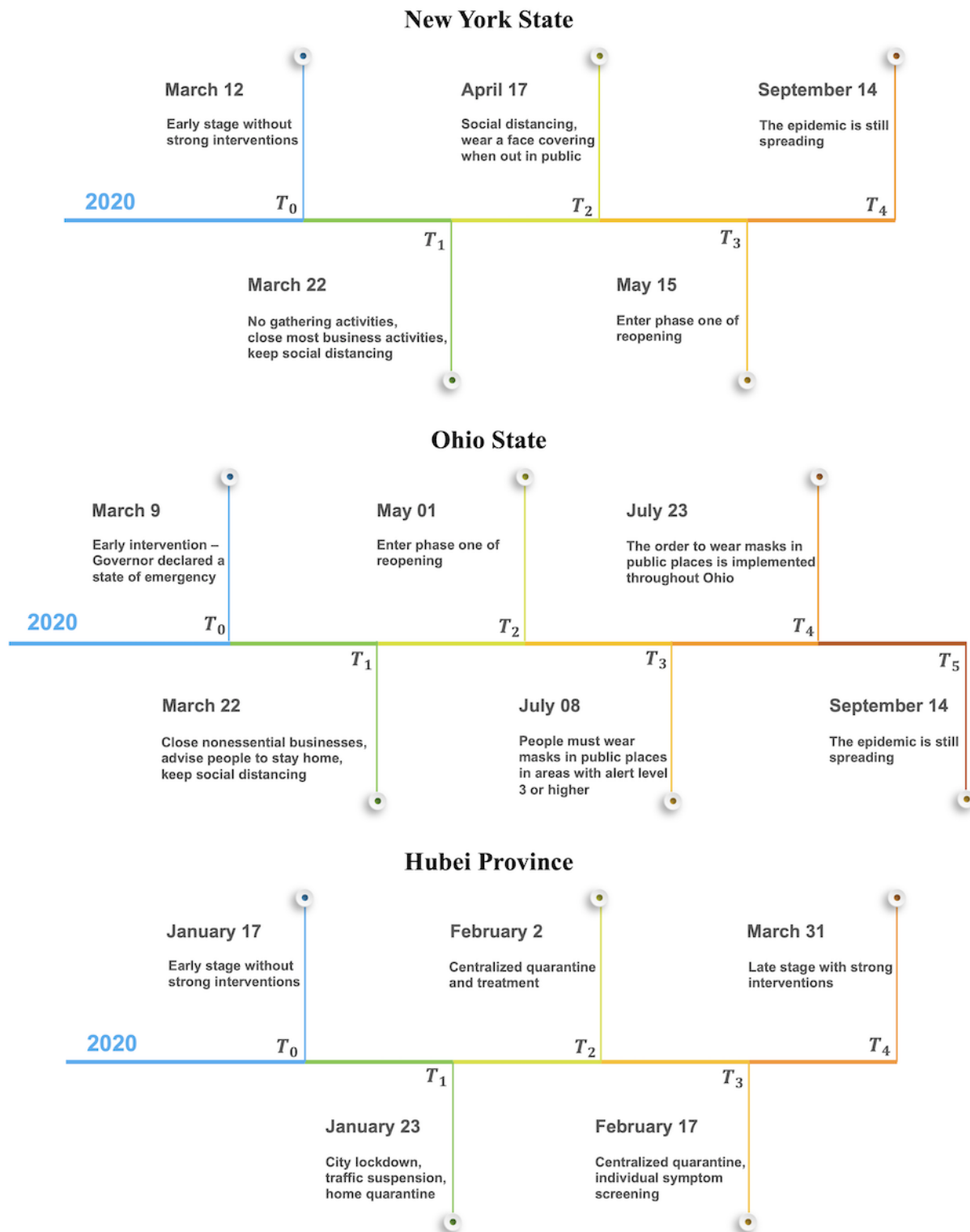
Public Health Interventions

Classification of Time Periods in New York

To better reflect the epidemic trends and corresponding interventions of COVID-19, four periods were classified according to data relevant for virus transmission in New York State (Figure 2). The first period was from March 12 to 22, 2020, the free virus transmission period. The second period was from March 22 to April 17. The governor of New York State, Andrew Cuomo, issued the “New York State on PAUSE” (Policies Assure Uniform Safety for Everyone) Executive Order on March 20, which took effect on March 22. This 10-point policy included a new directive that all nonessential businesses statewide must close in-office personnel functions, temporary banning of all nonessential gatherings of individuals of any size for any reason, and mandated social distancing of at least 6 feet from others for individuals in public. The third period was from April 17 to May 15. The governor announced another order that all people in New York would be required to wear a face covering when out in public and in situations where social distancing cannot be maintained. The fourth period started on May 15. Some regions of New York State started to enter the first phase of reopening. To reflect the effects of governmental public health policy in the different periods, we modeled the

transmission rates using piecewise exponential functions (see [Multimedia Appendix 1](#)).

Figure 2. Classification of time periods according to key events and interventions in New York State, Ohio State, and Hubei Province.



Classification of Time Periods in Ohio

We considered five time periods based on several key time points that could affect the virus’s spread in Ohio. Ohio was the state that took early actions against COVID-19. The first period was from March 9 to 22, 2020. The governor of Ohio, Mike DeWine, declared a state of emergency in Ohio on March 9 and announced several steps to fight against the spread of the

COVID-19 epidemic; before, there were no confirmed cases in Ohio. The second period was from March 22 to May 1. A statewide “stay at home” order was issued on March 22. The order included advising people to stay at home, closing most nonessential businesses, and requiring individuals in public to practice social distancing. The third period was from May 1 to July 8. Ohio entered the first phase of its reopening program.

The fourth period was from July 8 to 23, 2020. Mr DeWine announced that any county at level 3 or higher in the Public Health Advisory System must wear masks in public places. The fifth period started from July 23. Ohio mandated the use of masks and face coverings across the state while in public.

Classification of Time Periods in Hubei Province

We considered four time periods according to the critical dates that may have affected virus transmission in Hubei. The first period was from January 17 to 23, 2020, the Spring Festival period in China. There was a large-scale population flow, and there was no strong intervention to prevent and control the epidemic. The second period was from January 23 to February 2. The China's central government imposed a lockdown in Wuhan and other cities in Hubei to quarantine the center of the COVID-19 outbreak on January 23. The actions included suspending public transport, banning all vehicles in cities, blocking the main roads between cities, requiring people to wear masks in public places, and forbidding gathering activities. The third period was from February 2 to 17. Hubei successively opened several new temporary hospitals to treat patients with mild symptoms and isolate the infection source. The fourth period started on February 17. The government began the individual symptom screening for all residents.

The Effects of Medical Resources

In the early period of the COVID-19 pandemic, medical resources such as hospital beds, ICU beds, and ventilators fell short. During this period, the availability of the medical workforce was affected since many physicians and nurses were becoming ill or quarantined [22]. With the continuous allocation of more medical resources and the opening of new temporary hospitals, patients with mild disease got a better treatment. Therefore, we considered that the cure rate γ_m changed with time and modeled it with a three-parameter logistic function to reflect the continuous improvement of reactive medical resources in the three areas.

Statistical Analysis

We performed a Bayesian analysis with Markov chain Monte Carlo (MCMC) to fit the models to the COVID-19

epidemiological data in the three areas. To implement the MCMC algorithm, we followed the method by Raftery and Lewis [23]. After an initial number of 10,000 burn iterations, every 10th MCMC sample was retained from the next 200,000 samples. Thus, 20,000 samples of targeted posterior distributions were used to estimate the unknown parameters. The stability of the posterior distributions was checked by examining the graphics of the runs. The mathematical details of the dynamic SEIR model are presented in [Multimedia Appendix 1](#). We also developed an online R shiny app to help readers assess the models [24]. All analyses were done with R software (V3.6.3; R Foundation for Statistical Computing).

Results

Parameters

The parameters in the dynamic models included the transmission rates β_m and β_E ; the progression rates α_m , α_s , p_s , and p_c ; the recovery rates γ_m , γ_s , and γ_c ; the death rates q_s and q_c ; and the rate that recovered individuals become susceptible again, δ . Posterior means and 95% credible intervals (CIs) for the model parameters are presented in Table S1 in [Multimedia Appendix 1](#). Those estimated parameters varied for the three areas. Noticeably, we found that the rate δ was low and ignorable in all areas, which indicates that the patients who were cured had little chance to become susceptible again. The fitted curves for the epidemic trends of COVID-19 for the three areas are presented in Figure S1 in [Multimedia Appendix 1](#). The proposed models performed well in simultaneously fitting the multidimensional epidemic data.

Transmission Rates and Effective Reproduction Numbers



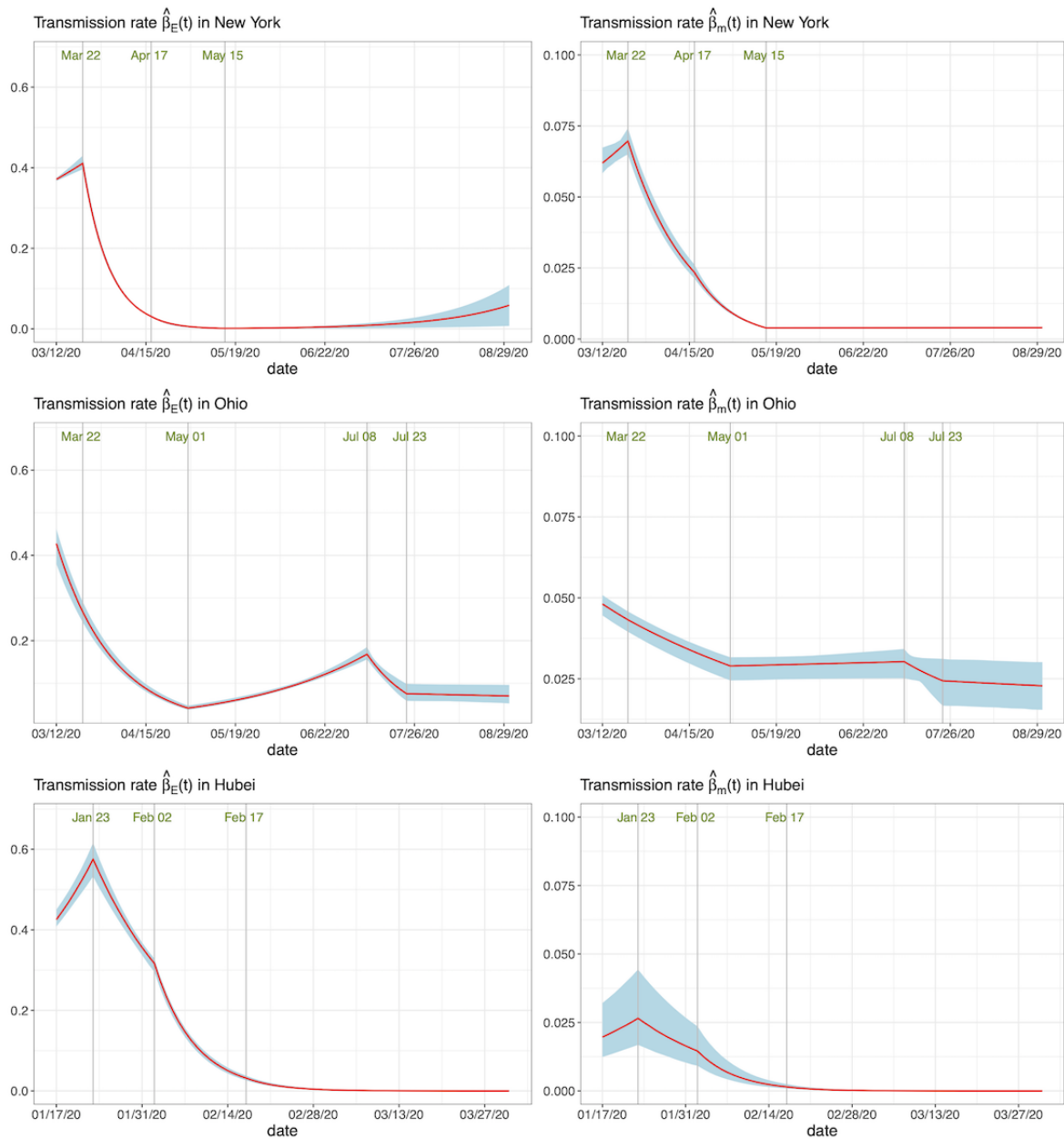
The estimated transmission rate functions  and  for the three areas are displayed in [Figure 3](#). The estimates of decay parameters with their 95% CIs and the mean differences between different periods are presented in Table S1 in [Multimedia Appendix 1](#).

Figure 3. The estimated time-varying transmission rates $\hat{\beta}_E(t)$ and $\hat{\beta}_m(t)$, in New York State, Ohio State, and Hubei Province. The solid lines denote the posterior mean curves, and the grey areas denote the 95% credible intervals.



In New York, the PAUSE Executive Order appeared effective. The transmission rates declined quickly after the order was executed. With the effects of the first and second orders, the rates continued decreasing after April 17, 2020. In Ohio, we noticed that the rates declined before the “stay at home” order because of the early interventions by the government. The transmission rates in Ohio were lower than those in New York before April.

However, the rates in Ohio started to increase after May 1, 2020, when Ohio entered the first phase of its reopening program. Ohio had a second wave of COVID-19 but New York did not in July. It might be because more strict reopening policies were implemented in New York after May. Ohio’s transmission rates decreased again after the order of mandatory use of masks and face coverings was implemented.

In Hubei, the transmission rate of the virus was growing rapidly in the first period because of the large floating population during the Spring Festival of China. In the second period, due to the city lockdown policy implemented, the transmission of the virus had been adequately controlled. In the third period, the transmission rates were further reduced because temporary hospitals effectively treated patients with mild symptoms and isolated the infection sources.

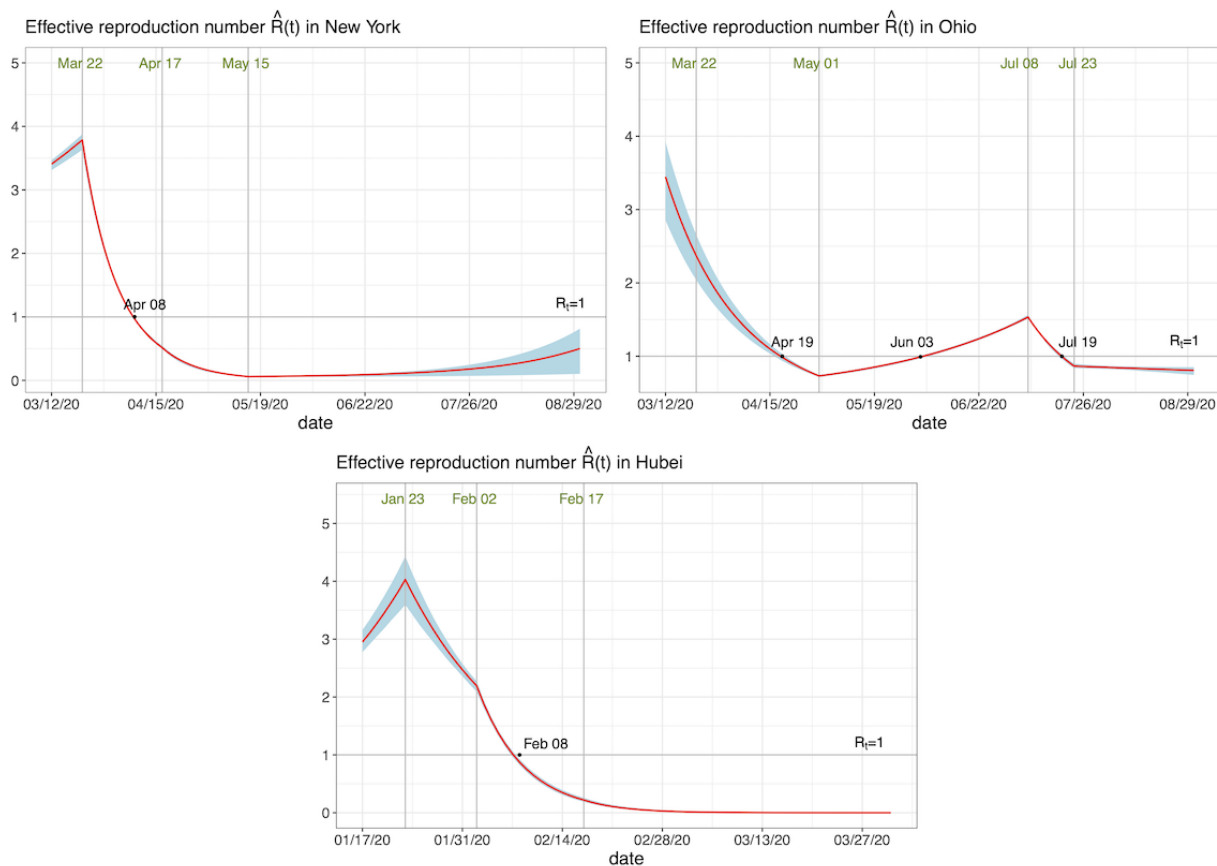
In all areas, the transmission rate of exposed individuals was higher than that of mild patients. The transmission rates of mild patients β_m in New York and Ohio were higher than in Hubei, which may be due to the policy of centralized treatment of mild patients in temporary hospitals in Hubei. This policy seemed to effectively reduce the contact between mild illness patients and susceptible people, thus reducing the transmission rate of mild patients. The public health interventions of social

distancing and home confinement played a significant role in preventing and controlling the disease in all areas. The decay rates of transmission were significantly changed (in a Bayesian sense) before and after implementing the interventions (Table S1 in [Multimedia Appendix 1](#)).

The estimated effective reproduction numbers \hat{R}_t in the three areas are displayed in [Figure 4](#). The solid lines indicate the

posterior mean curves, and the grey areas denote the 95% CIs. After the policies of social distancing, no gathering activities, and closure of business activities, \hat{R}_t gradually fell below 1.0 for all areas. However, in Ohio, \hat{R}_t gradually increased after entering the first phase of its reopening program, and exceeded 1.0 on June 3, 2020. It started to decrease after people were mandatorily required to use masks in public.

Figure 4. The estimated effective reproduction number \hat{R}_t in the three areas. The solid lines denote the posterior mean curves, and the grey areas denote the 95% credible intervals.



Estimated Parameters for COVID-19 Clinical Progression and Disease Severity

[Table 1](#) presents the estimated parameters and their 95% CIs for COVID-19 clinical progression and disease severity. The mean incubation periods were close in the three areas (New York: 6.99 days; Ohio: 6.20 days; Hubei: 6.55 days). However, the time from symptoms to hospital admission in New York and Ohio was longer than that in Hubei (16.84 days and 16.72 days vs 10.20 days, respectively). The time from hospital admission to critical care was shorter in New York and Ohio than that in Hubei (5.43 days and 5.32 days vs 8.49 days,

respectively). The time from hospital admission to death was shorter in New York and Ohio than that in Hubei (10.33 days and 11.25 days vs 13.40 days, respectively). The proportion of infected subjects progressing to the severe stage in New York, Ohio, and Hubei were 23.56%, 12.63%, and 30.92%, respectively. The proportions progressing to the critical stage were 14.91%, 6.41%, and 13.49%, respectively. The proportions progressing to the death stage were 8.00%, 5.17%, and 4.48%, respectively. These differences may be because of the different hospitalization and ICU admission criteria, and a mixed patient population.

Table 1. Posterior mean and 95% CIs for quantities of COVID-19 clinical progression and disease severity.

Quantities	New York State, posterior mean (95% CI ^a)	Ohio State, posterior mean (95% CI)	Hubei Province, posterior mean (95% CI)
Incubation period (days)	6.99 (6.84-7.17)	6.20 (5.55-6.91)	6.55 (6.28-7.00)
Time from symptoms to hospital admission (days)	16.84 (16.68-16.91)	16.72 (16.28-17.11)	10.20 (9.57-10.81)
Time from hospital admission to critical care (days)	5.43 (5.06-5.80)	5.32 (5.03-5.59)	8.49 (7.77-9.31)
Time from hospital admission to death (days)	10.33 (9.90-10.67)	11.25 (10.52-12.00)	13.40 (12.33-14.52)
Proportion of infected patients progressing to severe stage (%)	23.56 (23.05-24.29)	12.63 (12.02-13.24)	30.92 (29.01-32.88)
Proportion of infected patients progressing to critical stage (%)	14.91 (14.11-15.88)	6.41 (5.76-7.18)	13.49 (12.01-15.05)
Proportion of infected patients progressing to death stage (%)	8.00 (7.88-8.12)	5.17 (4.97-5.37)	4.48 (4.10-4.87)

^aCI: credible interval.



Prediction of Hospital Use

Since the COVID-19 pandemic in the United States was still ongoing, we applied our model to predict hospital use since September 1, 2020. Table S4 in [Multimedia Appendix 1](#) presents the predicted versus observed numbers of patients that were newly hospitalized with COVID-19 in New York and Ohio. The mean absolute percentage error (the common measure of prediction accuracy for forecasting) was reasonably low, with 15.15% (SE 3.57%) in New York and 2.07% (SE 0.42%) in Ohio.

Discussion

New York, Ohio, and Hubei were three representative areas hit by COVID-19 in the United States and China. Evaluating the effectiveness of their public health interventions on reducing disease burden and estimating hospital use through the available historical epidemiological data is vital since adequate hospital capacity is critical to saving lives during this ongoing pandemic. Our findings highlight that early intervention is crucial. Ohio has lower transmission rates than New York in the early stage of the pandemic because Ohio declared a state of emergency on March 9, 2020. We also found that wearing masks is critical in controlling disease transmission. Ohio had a second peak of the outbreak but New York did not after entering the phase of reopening. In comparing their policies, Ohio implemented the order of the mandatory use of masks in July, while New York implemented it in April.

We noticed that the centralized quarantine, in addition to social distancing and wearing masks, could play an important and indispensable role in preventing and controlling the disease. In

Hubei, the decay parameters in  and  significantly increased after the centralized quarantine was implemented, which indicated the disease transmission received further controls. During Hubei's lockdown, more than sixteen public venues such as exhibition centers and gymnasiums were converted into temporary hospitals to treat patients with mild symptoms and isolate the source of infections amid strained medical resources.

Before these hospitals, many confirmed cases were quarantined at home and stayed in their communities, which could easily lead to clustered infections in families and communities. In New York, there was no centralized quarantine intervention and the mild patients were required to quarantine at home. A recent survey of nearly 1300 patients with COVID-19 admitted to hospitals in New York in May 2020 showed that 83% of new patients were at home. The temporary hospitals that treat mild patients during the COVID-19 epidemic could be beneficial in effectively reducing the contact of mild illness patients and susceptible people, and further reducing the transmission rate.

Consistent with the results from the recent studies in Wuhan City, China [14,15,25,26], our results showed that public health interventions dramatically decreased the case incidence and reduced the demand for hospital and ICU beds in these areas. In Figures S3 and S4 in [Multimedia Appendix 1](#), we demonstrate a few simulation scenarios when interventions were not implemented. We found that COVID-19 would overwhelm the hospital bed capacity limits if the interventions were delayed or not implemented. One caveat in this conclusion is that our analyses looked at bed capacity and use at a state level. Health care use, however, is local: unless bed use is coordinated across the multiple hospital systems within a given state, patients may overwhelmingly “flock” to a handful of specialized hospitals and overwhelm them. In such situations, even if there is adequate capacity across the state, individual hospital systems may be overwhelmed. This calls attention to the importance of public health coordination of resources and strategies.

At present, the immunogenicity, efficacy, safety, production capacity, and availability of COVID-19 vaccines are not yet clear. It is crucial to maintain the transmission at a low level until a safe and effective COVID-19 vaccine is developed and widely used to establish a population immune barrier. The recent meta-analysis by Chu et al [27] confirmed evidence of moderate certainty that current policies of at least 1 m physical distancing were probably associated with a large reduction in infection and that distances of 2 m might be more effective. The public health interventions, including social distancing and wearing a face

covering, should be continued to avoid the next peak of the outbreak.

The advantage of our proposed statistical methods is that all dynamic parameters can be estimated from observed data using MCMC algorithms under the Bayesian modeling framework. It is unlike many other methods that simulated disease spread

with prespecified parameters. We hope our analysis provides data-driven evidence to potentially improve on whether, when, and how to adapt public health interventions in the future. As an increasing number of cases are still being identified in the United States, we believe our proposed model could help project hospital use during the COVID-19 outbreaks.

Acknowledgments

KF's research was supported by the Fundamental Research Funds for the Central Universities of China (20720181003) and National Bureau of Statistics Funds of China (2019LD02). KF and XW are senior authors who jointly correspond to this paper.

Authors' Contributions

XW and KF had the idea for and designed the study, had full access to all of the data in the study, and take responsibility for the integrity of the data and the accuracy of the data analysis. XW, RR, MWK, LJ, ZC, and KF drafted the paper. XW and RR did the analysis, and all authors critically revised the manuscript for important intellectual content and gave final approval for the version to be published. XW, RR, and KF collected the data. All authors agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Supplementary material.

[[DOCX File , 773 KB - publichealth_v6i4e25174_app1.docx](#)]

References

1. Huang C, Wang Y, Li X, Ren L, Zhao J, Hu Y, et al. Clinical features of patients infected with 2019 novel coronavirus in Wuhan, China. *Lancet* 2020 Feb 15;395(10223):497-506 [[FREE Full text](#)] [doi: [10.1016/S0140-6736\(20\)30183-5](https://doi.org/10.1016/S0140-6736(20)30183-5)] [Medline: [31986264](https://pubmed.ncbi.nlm.nih.gov/31986264/)]
2. Chen N, Zhou M, Dong X, Qu J, Gong F, Han Y, et al. Epidemiological and clinical characteristics of 99 cases of 2019 novel coronavirus pneumonia in Wuhan, China: a descriptive study. *Lancet* 2020 Feb 15;395(10223):507-513 [[FREE Full text](#)] [doi: [10.1016/S0140-6736\(20\)30211-7](https://doi.org/10.1016/S0140-6736(20)30211-7)] [Medline: [32007143](https://pubmed.ncbi.nlm.nih.gov/32007143/)]
3. Wang D, Hu B, Hu C, Zhu F, Liu X, Zhang J, et al. Clinical characteristics of 138 hospitalized patients with 2019 novel coronavirus-infected pneumonia in Wuhan, China. *JAMA* 2020 Mar 17;323(11):1061-1069 [[FREE Full text](#)] [doi: [10.1001/jama.2020.1585](https://doi.org/10.1001/jama.2020.1585)] [Medline: [32031570](https://pubmed.ncbi.nlm.nih.gov/32031570/)]
4. Guan WJ, Ni ZY, Hu Y, Liang WH, Ou CQ, He JX, China Medical Treatment Expert Group for Covid-19. Clinical characteristics of coronavirus disease 2019 in China. *N Engl J Med* 2020 Apr 30;382(18):1708-1720 [[FREE Full text](#)] [doi: [10.1056/NEJMoa2002032](https://doi.org/10.1056/NEJMoa2002032)] [Medline: [32109013](https://pubmed.ncbi.nlm.nih.gov/32109013/)]
5. Wu JT, Leung K, Leung GM. Nowcasting and forecasting the potential domestic and international spread of the 2019-nCoV outbreak originating in Wuhan, China: a modelling study. *Lancet* 2020 Feb 29;395(10225):689-697 [[FREE Full text](#)] [doi: [10.1016/S0140-6736\(20\)30260-9](https://doi.org/10.1016/S0140-6736(20)30260-9)] [Medline: [32014114](https://pubmed.ncbi.nlm.nih.gov/32014114/)]
6. Kucharski AJ, Russell TW, Diamond C, Liu Y, Edmunds J, Funk S, Centre for Mathematical Modelling of Infectious Diseases COVID-19 working group. Early dynamics of transmission and control of COVID-19: a mathematical modelling study. *Lancet Infect Dis* 2020 May;20(5):553-558 [[FREE Full text](#)] [doi: [10.1016/S1473-3099\(20\)30144-4](https://doi.org/10.1016/S1473-3099(20)30144-4)] [Medline: [32171059](https://pubmed.ncbi.nlm.nih.gov/32171059/)]
7. Yang Z, Zeng Z, Wang K, Wong S, Liang W, Zanin M, et al. Modified SEIR and AI prediction of the epidemics trend of COVID-19 in China under public health interventions. *J Thorac Dis* 2020 Mar;12(3):165-174. [doi: [10.21037/jtd.2020.02.64](https://doi.org/10.21037/jtd.2020.02.64)] [Medline: [32274081](https://pubmed.ncbi.nlm.nih.gov/32274081/)]
8. Zhao S, Lin Q, Ran J, Musa SS, Yang G, Wang W, et al. Preliminary estimation of the basic reproduction number of novel coronavirus (2019-nCoV) in China, from 2019 to 2020: A data-driven analysis in the early phase of the outbreak. *Int J Infect Dis* 2020 Mar;92:214-217 [[FREE Full text](#)] [doi: [10.1016/j.ijid.2020.01.050](https://doi.org/10.1016/j.ijid.2020.01.050)] [Medline: [32007643](https://pubmed.ncbi.nlm.nih.gov/32007643/)]
9. Fang Y, Nie Y, Penny M. Transmission dynamics of the COVID-19 outbreak and effectiveness of government interventions: a data-driven analysis. *J Med Virol* 2020 Jun;92(6):645-659 [[FREE Full text](#)] [doi: [10.1002/jmv.25750](https://doi.org/10.1002/jmv.25750)] [Medline: [32141624](https://pubmed.ncbi.nlm.nih.gov/32141624/)]
10. Tolles J, Luong T. Modeling epidemics with compartmental models. *JAMA* 2020 Jun 23;323(24):2515-2516. [doi: [10.1001/jama.2020.8420](https://doi.org/10.1001/jama.2020.8420)] [Medline: [32459319](https://pubmed.ncbi.nlm.nih.gov/32459319/)]

11. Moghadas SM, Shoukat A, Fitzpatrick MC, Wells CR, Sah P, Pandey A, et al. Projecting hospital utilization during the COVID-19 outbreaks in the United States. *Proc Natl Acad Sci U S A* 2020 Apr 21;117(16):9122-9126 [FREE Full text] [doi: [10.1073/pnas.2004064117](https://doi.org/10.1073/pnas.2004064117)] [Medline: [32245814](https://pubmed.ncbi.nlm.nih.gov/32245814/)]
12. Zhao S, Chen H. Modeling the epidemic dynamics and control of COVID-19 outbreak in China. *Quant Biol* 2020 Mar 11:1-9 [FREE Full text] [doi: [10.1007/s40484-020-0199-0](https://doi.org/10.1007/s40484-020-0199-0)] [Medline: [32219006](https://pubmed.ncbi.nlm.nih.gov/32219006/)]
13. Cavallo JJ, Donoho DA, Forman HP. Hospital capacity and operations in the coronavirus disease 2019 (COVID-19) pandemic—planning for the nth patient. *JAMA Health Forum* 2020 Mar 17;1(3):e200345. [doi: [10.1001/jamahealthforum.2020.0345](https://doi.org/10.1001/jamahealthforum.2020.0345)]
14. Tian H, Liu Y, Li Y, Wu C, Chen B, Kraemer MUG, et al. An investigation of transmission control measures during the first 50 days of the COVID-19 epidemic in China. *Science* 2020 May 08;368(6491):638-642 [FREE Full text] [doi: [10.1126/science.abb6105](https://doi.org/10.1126/science.abb6105)] [Medline: [32234804](https://pubmed.ncbi.nlm.nih.gov/32234804/)]
15. Pan A, Liu L, Wang C, Guo H, Hao X, Wang Q, et al. Association of public health interventions with the epidemiology of the COVID-19 outbreak in Wuhan, China. *JAMA* 2020 May 19;323(19):1915-1923 [FREE Full text] [doi: [10.1001/jama.2020.6130](https://doi.org/10.1001/jama.2020.6130)] [Medline: [32275295](https://pubmed.ncbi.nlm.nih.gov/32275295/)]
16. Grasselli G, Pesenti A, Cecconi M. Critical care utilization for the COVID-19 outbreak in Lombardy, Italy: early experience and forecast during an emergency response. *JAMA* 2020 Apr 28;323(16):1545-1546. [doi: [10.1001/jama.2020.4031](https://doi.org/10.1001/jama.2020.4031)] [Medline: [32167538](https://pubmed.ncbi.nlm.nih.gov/32167538/)]
17. Weissman GE, Crane-Droesch A, Chivers C, Luong T, Hanish A, Levy MZ, et al. Locally informed simulation to predict hospital capacity needs during the COVID-19 pandemic. *Ann Intern Med* 2020 Jul 07;173(1):21-28 [FREE Full text] [doi: [10.7326/M20-1260](https://doi.org/10.7326/M20-1260)] [Medline: [32259197](https://pubmed.ncbi.nlm.nih.gov/32259197/)]
18. Johns Hopkins Coronavirus Resource Center. URL: <https://coronavirus.jhu.edu/> [accessed 2020-12-16]
19. The COVID Tracking Project. URL: <https://covidtracking.com> [accessed 2020-12-16]
20. Hubei.gov.cn. URL: <http://wjw.hubei.gov.cn/> [accessed 2020-12-16]
21. The Novel Coronavirus Pneumonia Emergency Response Epidemiology Team. Vital surveillances: the epidemiological characteristics of an outbreak of 2019 novel coronavirus diseases (COVID-19) — China, 2020. *China CDC Weekly* 2020;2(8):113-122. [doi: [10.46234/ccdcw2020.032](https://doi.org/10.46234/ccdcw2020.032)]
22. Emanuel EJ, Persad G, Upshur R, Thome B, Parker M, Glickman A, et al. Fair allocation of scarce medical resources in the time of Covid-19. *N Engl J Med* 2020 May 21;382(21):2049-2055. [doi: [10.1056/NEJMs2005114](https://doi.org/10.1056/NEJMs2005114)] [Medline: [32202722](https://pubmed.ncbi.nlm.nih.gov/32202722/)]
23. Raftery AE, Lewis SM. [Practical Markov chain Monte Carlo]: comment: one long run with diagnostics: implementation strategies for Markov chain Monte Carlo. *Stat Sci* 1992 Nov;7(4):493-497. [doi: [10.1214/ss/1177011143](https://doi.org/10.1214/ss/1177011143)]
24. Dynamic SEIR Model for COVID-19 With Multiple Clinical Stages. URL: <http://riskcalc.org/DSEIR> [accessed 2020-12-16]
25. Prem K, Liu Y, Russell TW, Kucharski AJ, Eggo RM, Davies N, Centre for the Mathematical Modelling of Infectious Diseases COVID-19 Working Group, et al. The effect of control strategies to reduce social mixing on outcomes of the COVID-19 epidemic in Wuhan, China: a modelling study. *Lancet Public Health* 2020 May;5(5):e261-e270 [FREE Full text] [doi: [10.1016/S2468-2667\(20\)30073-6](https://doi.org/10.1016/S2468-2667(20)30073-6)] [Medline: [32220655](https://pubmed.ncbi.nlm.nih.gov/32220655/)]
26. Chinazzi M, Davis JT, Ajelli M, Gioannini C, Litvinova M, Merler S, et al. The effect of travel restrictions on the spread of the 2019 novel coronavirus (COVID-19) outbreak. *Science* 2020 Apr 24;368(6489):395-400 [FREE Full text] [doi: [10.1126/science.aba9757](https://doi.org/10.1126/science.aba9757)] [Medline: [32144116](https://pubmed.ncbi.nlm.nih.gov/32144116/)]
27. Chu D, Akl EA, Duda S, Solo K, Yaacoub S, Schünemann HJ, COVID-19 Systematic Urgent Review Group Effort (SURGE) study authors. Physical distancing, face masks, and eye protection to prevent person-to-person transmission of SARS-CoV-2 and COVID-19: a systematic review and meta-analysis. *Lancet* 2020 Jun 27;395(10242):1973-1987 [FREE Full text] [doi: [10.1016/S0140-6736\(20\)31142-9](https://doi.org/10.1016/S0140-6736(20)31142-9)] [Medline: [32497510](https://pubmed.ncbi.nlm.nih.gov/32497510/)]

Abbreviations

CI: credible interval

ICU: intensive care unit

MCMC: Markov chain Monte Carlo

PAUSE: Policies Assure Uniform Safety for Everyone

SEIR: susceptible-exposed-infectious-removed

WHO: World Health Organization

Edited by G Eysenbach; submitted 20.10.20; peer-reviewed by J Zhang; comments to author 11.11.20; revised version received 12.11.20; accepted 06.12.20; published 23.12.20.

Please cite as:

Wang X, Ren R, Kattan MW, Jehi L, Cheng Z, Fang K

Public Health Interventions' Effect on Hospital Use in Patients With COVID-19: Comparative Study

JMIR Public Health Surveill 2020;6(4):e25174

URL: <http://publichealth.jmir.org/2020/4/e25174/>

doi: [10.2196/25174](https://doi.org/10.2196/25174)

PMID: [33315585](https://pubmed.ncbi.nlm.nih.gov/33315585/)

©Xiaofeng Wang, Rui Ren, Michael W Kattan, Lara Jehi, Zhenshun Cheng, Kuangnan Fang. Originally published in JMIR Public Health and Surveillance (<http://publichealth.jmir.org>), 23.12.2020. This is an open-access article distributed under the terms of the Creative Commons Attribution License (<https://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in JMIR Public Health and Surveillance, is properly cited. The complete bibliographic information, a link to the original publication on <http://publichealth.jmir.org>, as well as this copyright and license information must be included.

Original Paper

Time Trends of the Public's Attention Toward Suicide During the COVID-19 Pandemic: Retrospective, Longitudinal Time-Series Study

Dayle Burnett¹, MSc; Valsamma Eapen^{2,3}, MBBS, PhD; Ping-I Lin^{2,3}, MHS, MD, PhD

¹Department of Women's and Children's Health, Uppsala University, Uppsala, Sweden

²School of Psychiatry, University of New South Wales, Kensington, Australia

³South Western Sydney Local Health District, Liverpool, Australia

Corresponding Author:

Ping-I Lin, MHS, MD, PhD

School of Psychiatry

University of New South Wales

Level 1, Australian Graduate School of Management Building Gate

11 Botany St

Kensington, 2052

Australia

Phone: 61 421315320

Email: pingi.lin@gmail.com

Abstract

Background: The COVID-19 pandemic has overwhelmed health care systems around the world. Emerging evidence has suggested that substantially few patients seek help for suicidality at clinical settings during the COVID-19 pandemic, which has elicited concerns of an imminent mental health crisis as the course of the pandemic continues to unfold. Clarifying the relationship between the public's attention to knowledge about suicide and the public's attention to knowledge about the COVID-19 pandemic may provide insight into developing prevention strategies for a putative surge of suicide in relation to the impact of the COVID-19 pandemic.

Objective: The goal of this retrospective, longitudinal time-series study is to understand the relationship between temporal trends of interest for the search term "suicide" and those of COVID-19-related terms, such as "social distancing," "school closure," and "lockdown."

Methods: We used the Google Trends platform to collect data on daily interest levels for search terms related to suicide, several other mental health-related issues, and COVID-19 over the period between February 14, 2020 and May 13, 2020. A correlational analysis was performed to determine the association between the search term "suicide" and COVID-19-related search terms in 16 countries. The Mann-Kendall test was used to examine significant differences between interest levels for the search term "suicide" before and after school closure.

Results: We found that interest levels for the search term "suicide" statistically significantly inversely correlated with interest levels for the search terms "COVID-19" or "coronavirus" in nearly all countries between February 14, 2020 and May 13, 2020. Additionally, search interest for the term "suicide" significantly and negatively correlated with that of many COVID-19-related search terms, and search interest varied between countries. The Mann-Kendall test was used to examine significant differences between search interest levels for the term "suicide" before and after school closure. The Netherlands ($P=.19$), New Zealand ($P=.003$), the United Kingdom ($P=.006$), and the United States ($P=.049$) showed significant negative trends in interest levels for suicide in the 2-week period preceding school closures. In contrast, interest levels for suicide had a significant positive trend in Canada ($P<.001$) and the United States ($P=.002$) after school closures.

Conclusions: The public's attention to suicide might inversely correlate with the public's attention to COVID-19-related issues. Additionally, several anticontagion policies, such as school closure, might have led to a turning point for mental health crises, because the attention to suicidality increased after restrictions were implemented. Our results suggest that an increased risk of suicidal ideation may ensue due to the ongoing anticontagion policies. Timely intervention strategies for suicides should therefore be an integral part of efforts to flatten the epidemic curve.

KEYWORDS

COVID-19; suicide; infodemiology; infoveillance; Google Trends; time trend; school closure; attention; mental health; crisis; time series

Introduction

In March 2020, the World Health Organization (WHO) declared the COVID-19 outbreak a pandemic. To curb the spread of the SARS-CoV-2 virus, governments worldwide have implemented public health measures, such as lockdown, isolation, and social distancing [1,2]. Although these measures are needed to protect physical health, the psychological impact of the pandemic is still emerging. To alleviate the concerns surrounding mental health, there has been a growing interest in telepsychiatry, which is defined as “the delivery of mental health care in the form of live and interactive videoconferencing” [3]. Telepsychiatry has proven to be an effective approach for helping people access mental health services in remote and underserved areas [4,5]. Although the implementation of such services may be useful during the pandemic, the full impact of COVID-19 is unlikely to be fully understood for some time.

Ongoing measures, such as isolation and social distancing, have separated people from their loved ones, leading to loneliness, boredom, and stress. Recent mental health studies on COVID-19 have revealed that these feelings are associated with common mental health disorders, such as depression and anxiety [6-8], and that the most vulnerable are those with preexisting mental health disorders [3-5]. Moreover, emerging evidence has suggested that the environmental nature of public health measures (eg, locations where quarantine is carried out) can lead to different effects on mental health. For instance, a recent study has revealed that poor housing is associated with an increased risk of depressive symptoms during lockdown [9].

Previous research on the psychological impact of quarantine from past epidemics has revealed that the fear of infection and lack of clear communication from governments are associated with a high prevalence of anxiety, exhaustion, psychological distress, and depression [10]. Furthermore, it has been reported that the lockdown, which has been enforced in many countries around the world, will have a substantial impact on the global economy; there have been predictions of an economic crisis and a large increase in unemployment worldwide, and unemployment is a well-recognized risk factor for suicide [11].

There is a growing body of literature that suggests suicide rates will increase during and after the pandemic due to anticontagion policies that increase social isolation and loneliness, which are well-known risk factors for suicide [12-15]. Indeed, there have been cases of COVID-19-related suicides in the United States, United Kingdom, Italy, Germany, Bangladesh, and India [14]. There have also been suggestions that the suicide rate will rise as the full economic and social impact of the pandemic unfolds. For example, higher suicide rates were observed among older adults in Hong Kong during the 2003 severe respiratory syndrome outbreak [16,17].

A considerable amount of published literature has examined the effects of the COVID-19 pandemic on the mental health of the general population; vulnerable people, including older adults and patients with chronic health conditions; patients with previous mental health disorders; and health care professionals [14,18-24]. These studies have indicated that suicide is likely to become an increasing issue as the pandemic continues, and that the pandemic has a long-term effect on the general population, not just those who are at an increased risk of suicide. Thus, to reduce the incidence of suicide during the COVID-19 pandemic, it is essential to mitigate risk factors, such as stress, anxiety, fear, and loneliness, in the general population.

Although reducing the number of social interactions remains one of the best methods to reduce the total burden of COVID-19, questions have been raised about control measures, such as school closure. The effectiveness of school closures has been suggested in previous studies on influenza outbreaks, which have reported that influenza transmission is higher in children than in adults [25]. However, in the context of COVID-19, data have indicated that COVID-19 transmission dynamics are different from influenza transmission dynamics; adults and older adults are more vulnerable to COVID-19 than the general population [26]. Furthermore, school closures can have large implications on society. In a recent review of school closure practices, Viner et al [27] found that such measures alone would only prevent 2%-4% of deaths, which is a much lower death prevention rate than that of other social distancing interventions. Viner et al [27] noted that the negative consequences of school closures include economic costs due to parents missing work to look after their children and reductions in health care staff resources, which in turn can negatively impact health care systems.

Due to the fast-moving nature of the pandemic, real-time data collection is needed to assess public interest in COVID-19. To date, the internet has been increasingly used as a source of health care information, especially Google, which is the world's most used search engine [28]. Google Trends is a website created by Google that analyses the popularity of the top search queries in Google Search; Google Trends has proven to be a powerful tool in tracking public interest in infectious diseases [29]. This study aims to explore the trends of COVID-19-related search terms and their association with common mental health disorders. In addition, this study aims to determine whether school closure, which we used as a proxy for nonpharmaceutical anticontagion policies, is associated with the risk of suicide.

Methods

Data Source

We used the web tool Google Trends to quantify web-based search interest in this study. The methodology we designed was based on the Google Trends Methodology Framework in

Infodemiology and Infoveillance [30]. Google Trends does not show actual search volume numbers. Instead, Google Trends provides the number of relative searches within a specified region and time for a particular search query by using a scale of 0-100. A value of 100 indicates the peak popularity of the query, whereas a score of 0 indicates a very small number of searches.

Data from Google Trends was compiled between February 14, 2020 and May 13, 2020. The following 16 countries were assessed in this study: Australia, Austria, Belgium, Canada, France, Germany, Ireland, Italy, the Netherlands, New Zealand, Portugal, Russia, Spain, Sweden, the United Kingdom, and the United States. The countries were chosen to represent locations in Europe with the largest number of COVID-19 deaths or those that were forecasted to experience a considerable number of deaths. We also included English-speaking countries outside of Europe, as our study was conducted in English. To determine whether the time since school closures correlated with the stringency level of anticontagion policies, we extracted stringency index data from the Our World in Data database [31] and school closure dates from the datasets provided by the United Nations Education, Scientific and Cultural Organization [32].

Search Terms

We used the following search queries to examine common mental health disorders: “suicide,” “depression,” and “anxiety.” To investigate any potential confounding factors related to suicide, we performed a manual search of the term “suicide” to find data on the suspected suicides of celebrities in the countries used in this study, by using advanced Google searches and web-based news articles. We tailored the dates to include results from between February 14 and May 13, 2020. We also studied the following COVID-19–related search queries: “Coronavirus (Virus),” “social distancing,” “school closure,” “self-isolation,” and “lockdown.” The search queries were chosen based on a recent review on suicide risk and prevention during the COVID-19 pandemic, in addition to keywords that were used in the media and government and WHO policy briefings [12]. It should be noted however that the term “Coronavirus (Virus)” was searched as a topic, which is defined as a group of terms that share the same concept in any language. This was done to include data on the different names associated with coronavirus, such as COVID-19. Although Google Trends provides users with the opportunity to compare up to 5 search queries at the same time, we decided to extract data for each search query individually and compare each query in its own distribution. The search was carried out using English terms.

Data analysis

Primary Analysis

We investigated the changes in trends for all the different search queries in Google Trends by using graphical representations for each country. This was carried out by using the smooth splines function in the ggplot2 package of R Studio. We used the Pearson correlation test to measure the strength of the association between each search query for each country. A 2-sided α value of $<.05$ was used as a cutoff to identify countries

that showed a significant association between the terms “school closure” and “suicide” for the next part of the analysis. The relationship between the time to school closure and the stringency index was examined using a generalized linear model, and the generalized estimating equation was used to correct for intracountry correlations [33].

Secondary Analysis

We carried out a Mann-Kendall test to compare the trends in suicide interest before and after school closures. We first identified the national school closure date for each of the selected countries, and then extracted Google Trends data for the search term “suicide” at 2 weeks before and after the school closure date for each country. The Mann-Kendall method is a nonparametric test that is used to detect statistically significant trends [34,35]. In this test, the null hypothesis (H_0) was that there was no trend in the number of suicide searches over time. The alternative hypothesis (H_1) was that there was a trend over time.

The Mann-Kendall S statistic was calculated using the following formula:

$$S = \sum_{j=1}^n \sum_{i=1}^{j-1} \text{sgn}(x_j - x_i)$$

In this formula, x_j and x_i are time series and n is the number of data points in the time series. With regard to calculating sgn , the following formula was used:

$$\text{sgn}(x) = \begin{cases} 1 & \text{if } x > 0 \\ 0 & \text{if } x = 0 \\ -1 & \text{if } x < 0 \end{cases}$$

The variance of the Mann-Kendall test was calculated as follows:

$$\text{Var}(S) = \frac{n(n-1)(2n+5)}{18} - \sum_{p=1}^q \frac{t_p(t_p-1)(t_p+1)}{18}$$

In this formula, q is the number of tied groups and t_p is the number of data values in the p th group.

The standard test statistic Z was calculated as follows:

$$Z = \frac{S - \frac{1}{2}}{\sqrt{\text{Var}(S)}}$$

Z follows the standard normal distribution. A positive Z value indicates a positive trend, whereas a negative Z value indicates a negative trend.

Results

Graphical Analysis

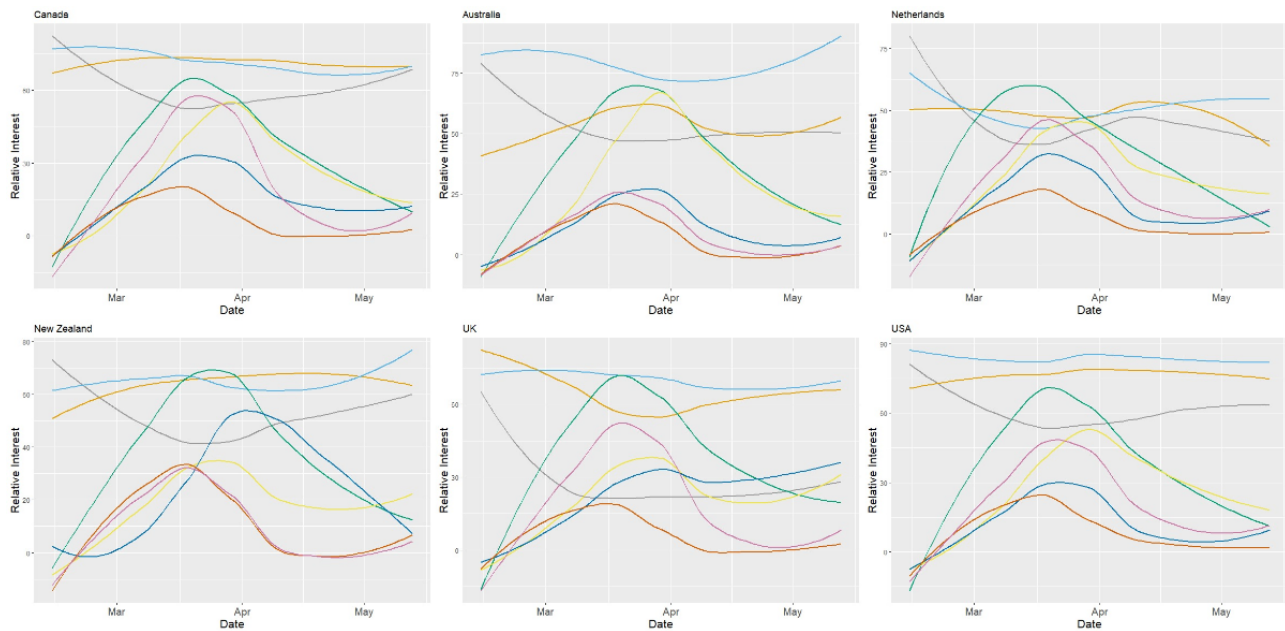
We assessed Google Trends data from the period between February 14, 2020 and May 13, 2020 for the selected search queries in the selected countries, as displayed in Figure 1. What stands out in all the figures are the common trends in COVID-19–related search queries across several countries. With regard to the search query “Coronavirus (Virus),” most countries showed a noticeable increase in the number of searches for terms related to coronavirus from the end of February until the middle of March, which is when interest for the term peaked, followed by a decline in the number of searches. The peak in

interest was most likely due to the WHO declaring COVID-19 a pandemic.

Although lockdown, social distancing, and self-isolation have been the main strategies for reducing the spread of COVID-19, it is clear from the graphs in the figures that the public's level of interest varied between countries and the different measures taken to combat the virus. For example, there was a greater

interest in searches for the term "lockdown" in Germany, New Zealand, Portugal, and Russia compared to other countries with different public health measures. Surprisingly, there was a large number of searches in Sweden for the term "lockdown," despite the fact that the government decided against imposing a lockdown, and instead relied on voluntary cooperation from its citizens [36].

Figure 1. Google Trends data for the selected 6 countries from between February 14, 2020 and May 13, 2020. The grey curve represents the relative interest for the term "suicide," the orange curve represents the relative interest for the term "depression," the light blue curve represents the relative interest for the term "anxiety," the green curve represents the relative interest for the term "Coronavirus (Virus)," the yellow curve represents the relative interest for the term "social distancing," the dark blue curve represents the relative interest for the term "lockdown," the red curve represents the relative interest for the term "school closure," and the purple curve represents the relative interest for the term "self-isolation." UK: United Kingdom; USA: United States of America.



In Australia, Austria, and Belgium, there was a greater interest in social distancing measures, while in the United Kingdom and Ireland, self-isolation generated greater interest. However, in Canada, the Netherlands, Spain, and the United States, the interest levels for self-isolation and social distancing produced very similar relative search volumes.

A closer inspection of the graphs revealed that the number of searches for the term "lockdown" in Austria, France, Ireland, Russia, Spain, and Sweden peaked at around the end of March, followed by a plateau. In other countries, the number of searches for "lockdown" decreased over time. In Germany, Portugal, and the United Kingdom, the interest levels for lockdown increased throughout the study period. Interestingly, searches for "lockdown" in Italy peaked during the middle of April. This could be due to Italy starting to ease lockdown measures, due to public interest in what activities could be carried out.

The interest levels for the term "school closures" varied between countries, and most countries showed a bell-shaped trend for the interest level. The variation in interest levels is most likely due to different countries announcing and enforcing school closures on different dates, as well as several countries imposing regional lockdowns before a national lockdown.

In most of the countries, the number of searches for the term "suicide" began to decrease toward the end of February and at

the beginning of March. Afterward, the number of searches started to increase again in several countries, namely France, Spain, Russia, New Zealand, and the Netherlands. In other countries, such as Australia, Belgium, and the United Kingdom, the search levels for the term "suicide" remained constant. It should be noted however that the peak in suicide-related search terms during February in the United Kingdom and, to a lesser extent, Ireland might have corresponded to the suicide death of television presenter Caroline Flack on February 15, 2020. This possibility was also highlighted in a similar study [37].

Levels of anxiety varied between the countries. In Ireland, the United Kingdom, and the United States, search interest levels for the term "anxiety" remained high throughout the study period. In Australia, Germany, New Zealand, and Portugal, the interest levels for "anxiety" increased after public health measures were implemented.

Correlational Analysis

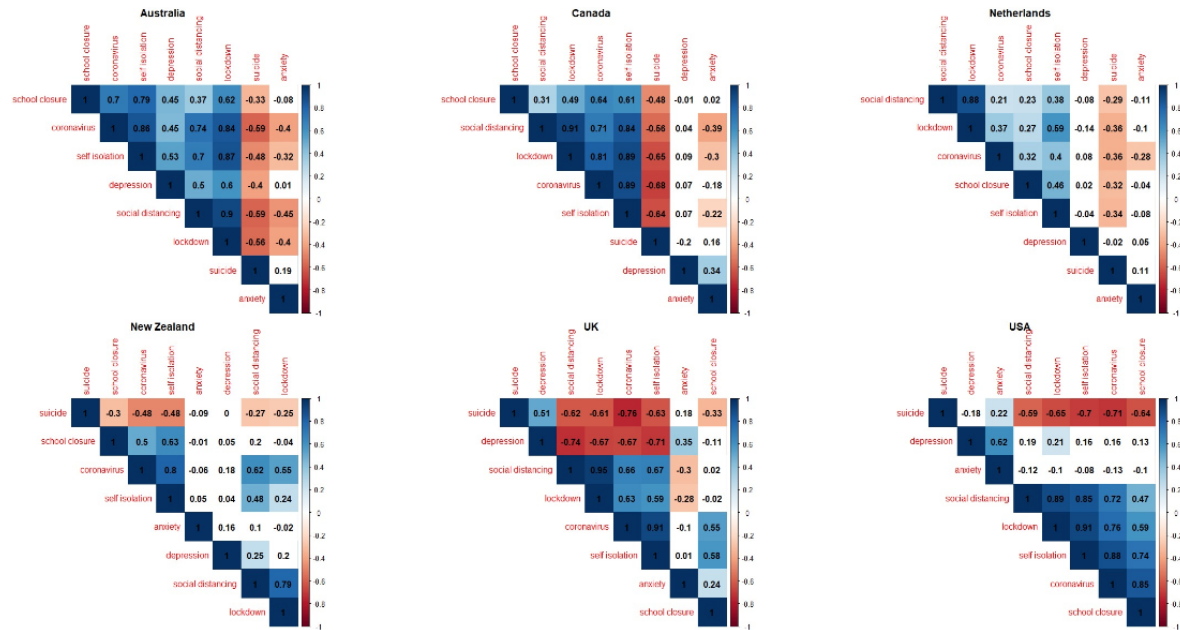
The results of the correlational analysis for selected countries are shown in Figure 2. The most interesting aspect of this figure is that searches for the term "suicide" did not significantly positively correlate with COVID-19-related queries. In Australia, Canada, Ireland, New Zealand, the United Kingdom, and the United States (ie, all the English-speaking countries), as well as in the Netherlands, all COVID-19-related search

queries were negatively associated with the term “suicide.” In Belgium, France, Italy, Spain, and Russia, searches for the term “suicide” were only significantly negatively associated with some of the other COVID-19-related queries.

The association between searches for the term “suicide” and searches for other mental health disorder-related terms varied between countries. Searches for the term “suicide” significantly positively correlated with searches for the term “depression” in France ($r= 0.5401, P<.001$), Germany ($r=0.2976, P=.004$),

Russia ($r= 0.3175, P=.002$), and the United Kingdom ($r= 0.5137, P<.001$), which is to be expected, as depression is a well-known risk factor for suicide [12]. However, in Australia, a negative correlation was observed ($r=-0.403, P<.001$). In addition, there was a weak significant correlation between the interest levels for the terms “suicide” and “anxiety” in the United States. Significant associations were observed between the terms “anxiety” and “depression” in Canada ($r=0.3429, P<.001$), Russia ($r=0.2389, P=.02$), the United Kingdom ($r=0.3506, P<.001$), and the United States ($r=0.6189, P<.001$).

Figure 2. Correlation matrices that represent the pairwise Pearson correlation coefficients of Google Trends search queries for 6 selected countries. Colored cells represent a statistical significance level of $P<.05$. UK: United Kingdom; USA: United States of America.



In most countries, strong positive correlations were observed between the search term “Coronavirus (Virus)” and other COVID-19-related search terms, which suggests that the public has been continuing to seek information about the SARS-CoV-2 virus and the measures that have been taken to curb the spread

of the virus. The results obtained from the correlational analysis between the terms “school closure” and “suicide” are shown in Table 1; only countries that showed a significant relationship between interest levels are shown.

Table 1. Results of the Pearson coefficient test between interest levels for the terms “school closure” and “suicide” based on Google Trends data from countries that showed a significant relationship between interest levels.

Country	r	P value
Australia	-0.33	<.001
Canada	-0.48	<.001
Netherlands	-0.32	.002
New Zealand	-0.3	.003
United Kingdom	-0.33	.001
United States	-0.64	<.001

Mann-Kendall Analysis

The time to school closure positively correlated with the stringency index level (coefficient: 0.97, $P<.001$). Figure 3 shows the trend in suicide-related search queries during the school closure period in countries where a significant association between the search terms “suicide” and “school closure” was found, based on Google Trends data. From the graphs, we can see that there was a decrease in the interest of suicide in all the

countries before school closure, whereas an increase in the interest levels for suicide occurred after school closure.

The Mann-Kendall test was applied on a daily basis to detect trends in the interest levels for suicide before and after countries’ respective school closure period. Table 2 shows the test results in terms of the Mann-Kendall score (S) and Z statistic. Of the 6 countries, the Netherlands ($P=.19$), New Zealand ($P=.003$), the United Kingdom ($P=.006$), and the United States ($P=.049$)

showed a significant negative trend in the interest levels for suicide in the 2-week period leading up to school closure. New Zealand showed the largest decrease in the number of searches related to suicide in the 2 weeks leading up to the school closure.

No significant trends were found in other countries. In contrast, the interest levels for suicide significantly positively correlated in Canada ($P < .001$) and the United States ($P = .002$) after schools closed. This trend was larger in Canada than in the United States.

Figure 3. Relative search interest level for the term “suicide” during the school closure period in selected countries. The dashed vertical line indicates the national school closure date. UK: United Kingdom; USA: United States of America.

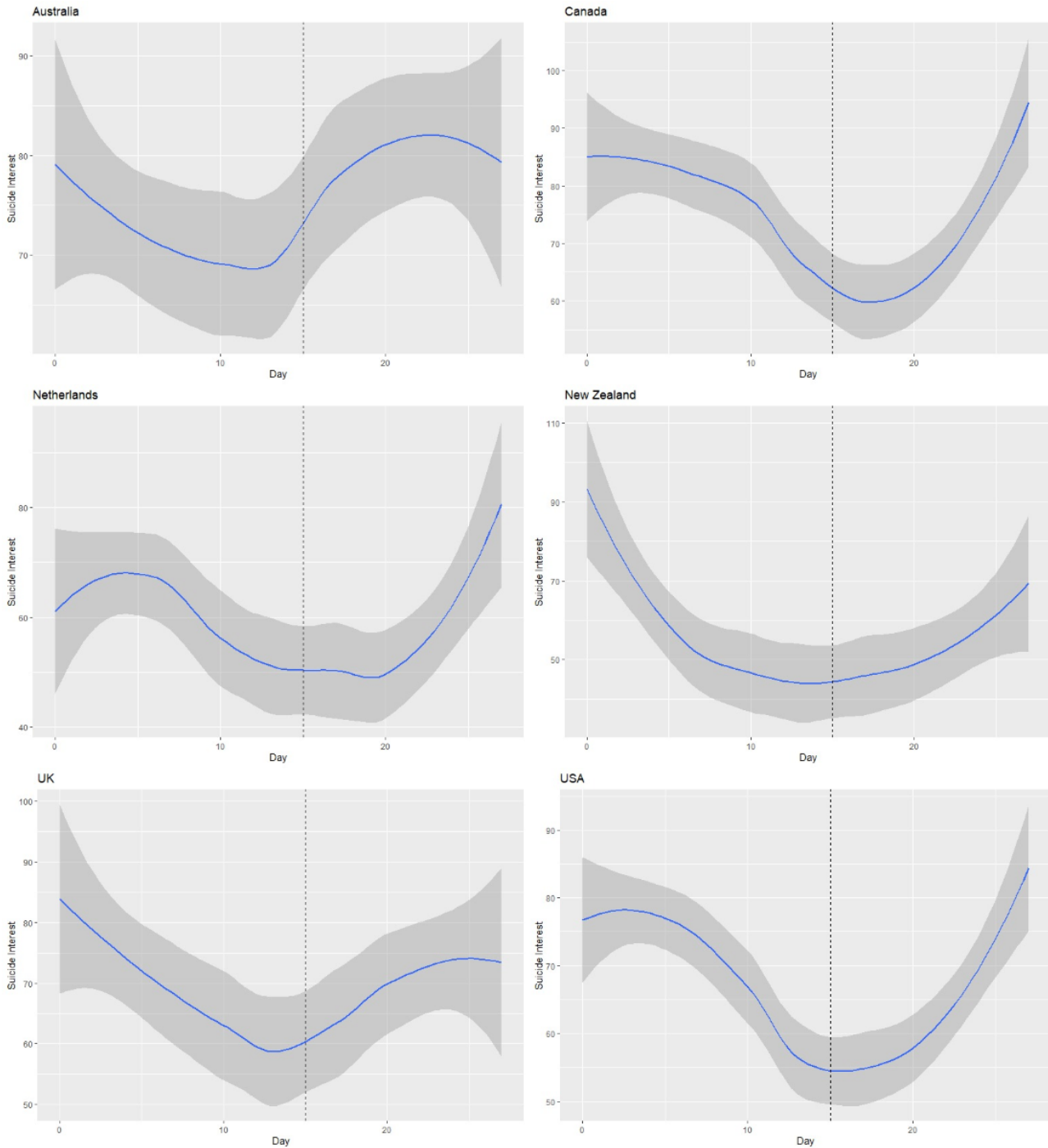


Table 2. Mann-Kendall test results for the comparison between suicide interest levels 2 weeks before school closure and 2 weeks after school closure for selected countries.

Country	Before school closure			After school closure		
	<i>S</i>	<i>Z</i>	<i>P</i> value	<i>S</i>	<i>Z</i>	<i>P</i> value
Australia	-25	-1.31	.19	13	0.66	.51
Canada	-23	-1.21	.23	72	3.9	<.001
Netherlands	-25	-1.32	.19	34	1.81	.07
New Zealand	-54	-2.91	.003	29	1.53	.13
United Kingdom	-51	-2.75	.006	17	0.88	.38
United States	-36	-1.97	.049	57	3.07	.002

Discussion

Principal Findings

By using web-based search interest as a proxy for the public's attention to specific terms, we found that the attention to terms related to COVID-19 surged following the COVID-19 outbreak in February 2020 and peaked between late March and mid-April 2020, which is when attention to suicide and other mental health issues started and continued to decline. Attention seems to have shifted from COVID-19 to suicide and other mental health-related issues after anticontagion policies, such as school closures, were enacted in many countries.

Our initial results are in line with recent studies, which have indicated that the number of searches related to COVID-19 rose during the peak of the pandemic [38-40]. However, we also found variations between different COVID-19-related search terms between different countries. This is most likely due to different countries being at different stages during the pandemic. Italy was the first country in Europe to implement a lockdown, and this was swiftly followed by many Western European countries implementing lockdown. Moreover, it is important to take into consideration the different strategies that were executed by different countries when interpreting these results. For example, while most countries in Europe implemented a full or partial lockdown, Sweden took a different route and emphasized the importance of social distancing.

In this study, we found that searches for the term "suicide" increased after anticontagion measures, such as school closures, were enforced. These findings are consistent with those from studies that used Google Trends to explore the changes in the public's search behaviors during the pandemic [37,41]. A note of caution is due, however, when comparing this study to previous research, as our study used school closure during the pandemic as a proxy, whereas most studies have focused on lockdown. Nonetheless, school closures can be regarded as a form of quarantine, and the adverse effects of school closures mainly impact certain population groups, such as children and adolescents, parents, and health care workers [26].

Limitations

Despite the strengths of this study, there are several limitations to consider when interpreting the results. First, this study focused on the 90-day period ensuing the outbreak. The results might have led to different conclusions if data from a longer period

of time were analyzed. However, we intended to evaluate the short-term impact of anticontagion policies by using school closure as a proxy. Therefore, the selected period of time might provide more relevant information. Second, the data was extracted from Google Trends, which only provides data on relative search volumes. If absolute numbers were provided instead of relative search volumes, a better comparison between countries could have been made, and more accurate results could have been obtained. Third, we did not adjust for the possible confounding effects of sociodemographic factors in the analyses. Economic downturn factors, such as job loss, may mediate or confound the association between the COVID-19-related events and the public's interest in suicidality. However, the goal of this study was to identify patterns in the public's attention toward suicidality in relation to COVID-19 instead of focusing on the causal relationship between the two. Therefore, the lack of taking mediators or confounders into consideration would not have affected our conclusions. However, the validity of Google Trends search interest for the behavioral forecasting of suicide rates may be low, because users' characteristics and motivations are unknown [42]. A recent study has shown that web-based search interest levels with regard to suicidality may concurrently correlate with the volume of aggregate incidents of suicidality at the population level [43]. Therefore, we believe that this study can provide insight into the temporal trend of imminent suicidal risk in different populations. Fourth, only English search terms were used in this study, and this could potentially restrict one's ability to make generalizations based on the study findings. We chose not to translate search terms because this approach requires a comprehensive understanding of each language to ensure that the key concepts of search terms are studied sufficiently. Although Google Trends provides users with the option of using topics (ie, a group of search terms that Google identified to share similar meanings across languages and countries), search terms such as "school closure" and "self-isolation" were unavailable at the time of writing. This approach could lead to obtaining data from users that only searched for a term in English in non-English-speaking countries (eg, France). Further, we examined the search interest levels for the term "lockdown" in France as an example, based on separate Google "Topics" and "Search Term" values. We found that these 2 values highly correlated with each other ($r=0.95$, $P<.001$) in countries where English is not the primary language, such as France. Since our study did not intend to compare search interest levels between different countries, this limitation does

not affect our conclusion. Finally, this study only used Google Trends to compare time trends during the pandemic. However, we do recognize that other platforms, such as Twitter, may have also been useful in identifying the public's concerns.

Public and Clinical Implications

Based on the growing body of literature on the impact of COVID-19, it is clear that mental health and psychological considerations are paramount. The findings from this study validate and extend previous work that used Google Trends to track public concerns.

The use of Google Trends in this study has important policy implications. For example, school closures have led to an increase in searches for the term "suicide," which suggests that people's mental health may have been affected by school

closures. Thus, policymakers will need to face the challenges of combating the virus through anticontagion policies while also reducing unintended consequences, particularly the consequences on mental health.

To conclude, our findings suggest that the consequences of the COVID-19 pandemic vary depending on countries' public health anticontagion measures. Although our study focused on high-income countries, it is important to recognize the potential impact our findings have on resource-poor settings, where mental health support is lacking. We believe that our results provide insight into the importance of integrating mental health services into anticontagion policies, as there is an urgent need to address how the mental health consequences of the pandemic can be mitigated, should similar outbreaks occur in the future [44].

Acknowledgments

The authors acknowledge Google Trends for providing data for this study

Conflicts of Interest

None declared.

References

1. Dsouza DD, Quadros S, Hyderabadwala ZJ, Mamun MA. Aggregated COVID-19 suicide incidences in India: Fear of COVID-19 infection is the prominent causative factor. *Psychiatry Res* 2020 Aug;290:113145. [doi: [10.1016/j.psychres.2020.113145](https://doi.org/10.1016/j.psychres.2020.113145)] [Medline: [32544650](https://pubmed.ncbi.nlm.nih.gov/32544650/)]
2. Zhou X, Snoswell CL, Harding LE, Bambling M, Edirippulige S, Bai X, et al. The Role of Telehealth in Reducing the Mental Health Burden from COVID-19. *Telemed J E Health* 2020 Apr;26(4):377-379. [doi: [10.1089/tmj.2020.0068](https://doi.org/10.1089/tmj.2020.0068)] [Medline: [32202977](https://pubmed.ncbi.nlm.nih.gov/32202977/)]
3. Costanza A, Mazzola V, Radomska M, Amerio A, Aguglia A, Prada P, et al. Who Consult an Adult Psychiatric Emergency Department? Pertinence of Admissions and Opportunities for Telepsychiatry. *Medicina (Kaunas)* 2020 Jun 13;56(6):295 [FREE Full text] [doi: [10.3390/medicina56060295](https://doi.org/10.3390/medicina56060295)] [Medline: [32545811](https://pubmed.ncbi.nlm.nih.gov/32545811/)]
4. Bhugra D, Tasman A, Pathare S, Priebe S, Smith S, Torous J, et al. The WPA-Lancet Psychiatry Commission on the Future of Psychiatry. *Lancet Psychiatry* 2017 Oct;4(10):775-818. [doi: [10.1016/S2215-0366\(17\)30333-4](https://doi.org/10.1016/S2215-0366(17)30333-4)] [Medline: [28946952](https://pubmed.ncbi.nlm.nih.gov/28946952/)]
5. Amerio A, Odone A, Marzano L, Costanza A, Aguglia A, Serafini G, et al. Covid-19: The last call for telepsychiatry. *Acta Biomed*. Epub ahead of print 2020 Jul 28;91(3) [FREE Full text] [doi: [10.23750/abm.v91i3.10337](https://doi.org/10.23750/abm.v91i3.10337)] [Medline: [32921742](https://pubmed.ncbi.nlm.nih.gov/32921742/)]
6. Thakur V, Jain A. COVID 2019-suicides: A global psychological pandemic. *Brain Behav Immun* 2020 Aug;88:952-953 [FREE Full text] [doi: [10.1016/j.bbi.2020.04.062](https://doi.org/10.1016/j.bbi.2020.04.062)] [Medline: [32335196](https://pubmed.ncbi.nlm.nih.gov/32335196/)]
7. Mamun MA, Griffiths MD. First COVID-19 suicide case in Bangladesh due to fear of COVID-19 and xenophobia: Possible suicide prevention strategies. *Asian J Psychiatr* 2020 Jun;51:102073 [FREE Full text] [doi: [10.1016/j.ajp.2020.102073](https://doi.org/10.1016/j.ajp.2020.102073)] [Medline: [32278889](https://pubmed.ncbi.nlm.nih.gov/32278889/)]
8. Courtet P, Olié E, Debien C, Vaiva G. Keep Socially (but Not Physically) Connected and Carry on: Preventing Suicide in the Age of COVID-19. *J Clin Psychiatry* 2020 Apr 14;81(3):20com13370 [FREE Full text] [doi: [10.4088/JCP.20com13370](https://doi.org/10.4088/JCP.20com13370)] [Medline: [32297718](https://pubmed.ncbi.nlm.nih.gov/32297718/)]
9. Amerio A, Brambilla A, Morganti A, Aguglia A, Bianchi D, Santi F, et al. COVID-19 Lockdown: Housing Built Environment's Effects on Mental Health. *Int J Environ Res Public Health* 2020 Aug 17;17(16):5973 [FREE Full text] [doi: [10.3390/ijerph17165973](https://doi.org/10.3390/ijerph17165973)] [Medline: [32824594](https://pubmed.ncbi.nlm.nih.gov/32824594/)]
10. Brooks SK, Webster RK, Smith LE, Woodland L, Wessely S, Greenberg N, et al. The psychological impact of quarantine and how to reduce it: rapid review of the evidence. *Lancet* 2020 Mar 14;395(10227):912-920 [FREE Full text] [doi: [10.1016/S0140-6736\(20\)30460-8](https://doi.org/10.1016/S0140-6736(20)30460-8)] [Medline: [32112714](https://pubmed.ncbi.nlm.nih.gov/32112714/)]
11. Kawohl W, Nordt C. COVID-19, unemployment, and suicide. *Lancet Psychiatry* 2020 May;7(5):389-390 [FREE Full text] [doi: [10.1016/S2215-0366\(20\)30141-3](https://doi.org/10.1016/S2215-0366(20)30141-3)] [Medline: [32353269](https://pubmed.ncbi.nlm.nih.gov/32353269/)]
12. Gunnell D, Appleby L, Arensman E, Hawton K, John A, Kapur N, COVID-19 Suicide Prevention Research Collaboration. Suicide risk and prevention during the COVID-19 pandemic. *Lancet Psychiatry* 2020 Jun;7(6):468-471 [FREE Full text] [doi: [10.1016/S2215-0366\(20\)30171-1](https://doi.org/10.1016/S2215-0366(20)30171-1)] [Medline: [32330430](https://pubmed.ncbi.nlm.nih.gov/32330430/)]

13. Niederkrotenthaler T, Gunnell D, Arensman E, Pirkis J, Appleby L, Hawton K, International COVID-19 Suicide Prevention Research Collaboration. Suicide Research, Prevention, and COVID-19. *Crisis* 2020 Sep;41(5):321-330 [FREE Full text] [doi: [10.1027/0227-5910/a000731](https://doi.org/10.1027/0227-5910/a000731)] [Medline: [32716205](https://pubmed.ncbi.nlm.nih.gov/32716205/)]
14. Sher L. The impact of the COVID-19 pandemic on suicide rates. *QJM* 2020 Oct 01;113(10):707-712 [FREE Full text] [doi: [10.1093/qjmed/hcaa202](https://doi.org/10.1093/qjmed/hcaa202)] [Medline: [32539153](https://pubmed.ncbi.nlm.nih.gov/32539153/)]
15. Reger MA, Stanley IH, Joiner TE. Suicide Mortality and Coronavirus Disease 2019-A Perfect Storm? *JAMA Psychiatry*. Epub ahead of print 2020 Apr 10. [doi: [10.1001/jamapsychiatry.2020.1060](https://doi.org/10.1001/jamapsychiatry.2020.1060)] [Medline: [32275300](https://pubmed.ncbi.nlm.nih.gov/32275300/)]
16. Cheung YT, Chau PH, Yip PSF. A revisit on older adults suicides and Severe Acute Respiratory Syndrome (SARS) epidemic in Hong Kong. *Int J Geriatr Psychiatry* 2008 Dec;23(12):1231-1238. [doi: [10.1002/gps.2056](https://doi.org/10.1002/gps.2056)] [Medline: [18500689](https://pubmed.ncbi.nlm.nih.gov/18500689/)]
17. Wasserman IM. The impact of epidemic, war, prohibition and media on suicide: United States, 1910-1920. *Suicide Life Threat Behav* 1992;22(2):240-254. [Medline: [1626335](https://pubmed.ncbi.nlm.nih.gov/1626335/)]
18. Shi L, Lu ZA, Que JY, Huang XL, Liu L, Ran MS, et al. Prevalence of and Risk Factors Associated With Mental Health Symptoms Among the General Population in China During the Coronavirus Disease 2019 Pandemic. *JAMA Netw Open* 2020 Jul 01;3(7):e2014053 [FREE Full text] [doi: [10.1001/jamanetworkopen.2020.14053](https://doi.org/10.1001/jamanetworkopen.2020.14053)] [Medline: [32609353](https://pubmed.ncbi.nlm.nih.gov/32609353/)]
19. Montemurro N. The emotional impact of COVID-19: From medical staff to common people. *Brain Behav Immun* 2020 Jul;87:23-24 [FREE Full text] [doi: [10.1016/j.bbi.2020.03.032](https://doi.org/10.1016/j.bbi.2020.03.032)] [Medline: [32240766](https://pubmed.ncbi.nlm.nih.gov/32240766/)]
20. Yao H, Chen JH, Xu YF. Patients with mental health disorders in the COVID-19 epidemic. *Lancet Psychiatry* 2020 Apr;7(4):e21 [FREE Full text] [doi: [10.1016/S2215-0366\(20\)30090-0](https://doi.org/10.1016/S2215-0366(20)30090-0)] [Medline: [32199510](https://pubmed.ncbi.nlm.nih.gov/32199510/)]
21. Kang L, Ma S, Chen M, Yang J, Wang Y, Li R, et al. Impact on mental health and perceptions of psychological care among medical and nursing staff in Wuhan during the 2019 novel coronavirus disease outbreak: A cross-sectional study. *Brain Behav Immun* 2020 Jul;87:11-17 [FREE Full text] [doi: [10.1016/j.bbi.2020.03.028](https://doi.org/10.1016/j.bbi.2020.03.028)] [Medline: [32240764](https://pubmed.ncbi.nlm.nih.gov/32240764/)]
22. Que J, Shi L, Deng J, Liu J, Zhang L, Wu S, et al. Psychological impact of the COVID-19 pandemic on healthcare workers: a cross-sectional study in China. *Gen Psychiatr* 2020;33(3):e100259 [FREE Full text] [doi: [10.1136/gpsych-2020-100259](https://doi.org/10.1136/gpsych-2020-100259)] [Medline: [32596640](https://pubmed.ncbi.nlm.nih.gov/32596640/)]
23. Amerio A, Bianchi D, Santi F, Costantini L, Odone A, Signorelli C, et al. Covid-19 pandemic impact on mental health: a web-based cross-sectional survey on a sample of Italian general practitioners. *Acta Biomed* 2020 May 11;91(2):83-88 [FREE Full text] [doi: [10.23750/abm.v91i2.9619](https://doi.org/10.23750/abm.v91i2.9619)] [Medline: [32420931](https://pubmed.ncbi.nlm.nih.gov/32420931/)]
24. Stuijzand S, Deforges C, Sandoz V, Jaques C, Elmers J, Horsch A. Psychological Impact of an Epidemic/Pandemic on the Mental Health of Healthcare Professionals: A Rapid Review. *BMC Public Health Preprint* posted online on August 4, 2020. [doi: [10.21203/rs.3.rs-30156/v2](https://doi.org/10.21203/rs.3.rs-30156/v2)]
25. Esposito S, Principi N. School Closure During the Coronavirus Disease 2019 (COVID-19) Pandemic: An Effective Intervention at the Global Level? *JAMA Pediatr* 2020 Oct 01;174(10):921-922. [doi: [10.1001/jamapediatrics.2020.1892](https://doi.org/10.1001/jamapediatrics.2020.1892)] [Medline: [32401277](https://pubmed.ncbi.nlm.nih.gov/32401277/)]
26. Ludvigsson JF. Systematic review of COVID-19 in children shows milder cases and a better prognosis than adults. *Acta Paediatr* 2020 Jun;109(6):1088-1095 [FREE Full text] [doi: [10.1111/apa.15270](https://doi.org/10.1111/apa.15270)] [Medline: [32202343](https://pubmed.ncbi.nlm.nih.gov/32202343/)]
27. Viner RM, Russell SJ, Croker H, Packer J, Ward J, Stansfield C, et al. School closure and management practices during coronavirus outbreaks including COVID-19: a rapid systematic review. *Lancet Child Adolesc Health* 2020 May;4(5):397-404 [FREE Full text] [doi: [10.1016/S2352-4642\(20\)30095-X](https://doi.org/10.1016/S2352-4642(20)30095-X)] [Medline: [32272089](https://pubmed.ncbi.nlm.nih.gov/32272089/)]
28. Barros JM, Melia R, Francis K, Bogue J, O'Sullivan M, Young K, et al. The Validity of Google Trends Search Volumes for Behavioral Forecasting of National Suicide Rates in Ireland. *Int J Environ Res Public Health* 2019 Sep 02;16(17):3201 [FREE Full text] [doi: [10.3390/ijerph16173201](https://doi.org/10.3390/ijerph16173201)] [Medline: [31480718](https://pubmed.ncbi.nlm.nih.gov/31480718/)]
29. Yang S, Santillana M, Kou SC. Accurate estimation of influenza epidemics using Google search data via ARGO. *Proc Natl Acad Sci U S A* 2015 Nov 24;112(47):14473-14478 [FREE Full text] [doi: [10.1073/pnas.1515373112](https://doi.org/10.1073/pnas.1515373112)] [Medline: [26553980](https://pubmed.ncbi.nlm.nih.gov/26553980/)]
30. Mavragani A, Ochoa G. Google Trends in Infodemiology and Infoveillance: Methodology Framework. *JMIR Public Health Surveill* 2019 May 29;5(2):e13439 [FREE Full text] [doi: [10.2196/13439](https://doi.org/10.2196/13439)] [Medline: [31144671](https://pubmed.ncbi.nlm.nih.gov/31144671/)]
31. Coronavirus Pandemic (COVID-19) - Statistics and Research - Our World in Data. Our World in Data. URL: <https://ourworldindata.org/coronavirus> [accessed 2020-09-28]
32. School closures caused by Coronavirus (Covid-19). United Nations Educational, Scientific and Cultural Organization. URL: <https://en.unesco.org/covid19/educationresponse> [accessed 2020-09-28]
33. Liang KY, Zeger SL. Longitudinal data analysis using generalized linear models. *Biometrika* 1986 Apr;73(1):13-22 [FREE Full text] [doi: [10.1093/biomet/73.1.13](https://doi.org/10.1093/biomet/73.1.13)]
34. Mann HB. Nonparametric Tests Against Trend. *Econometrica* 1945 Jul;13(3):245-259. [doi: [10.2307/1907187](https://doi.org/10.2307/1907187)]
35. Kendall MG. Rank Correlation Measures. London: Charles Griffin; 1975.
36. Esaiasson P, Sohlberg J, Gherseti M, Johansson B. How the coronavirus crisis affects citizen trust in government institutions and in unknown others – Evidence from “the Swedish Experiment”. *SocArXiv Preprint* posted online on April 29, 2020. [doi: [10.31235/osf.io/6yw9r](https://doi.org/10.31235/osf.io/6yw9r)]
37. Knipe D, Evans H, Marchant A, Gunnell D, John A. Mapping population mental health concerns related to COVID-19 and the consequences of physical distancing: a Google trends analysis. *Wellcome Open Res* 2020;5:82 [FREE Full text] [doi: [10.12688/wellcomeopenres.15870.2](https://doi.org/10.12688/wellcomeopenres.15870.2)] [Medline: [32671230](https://pubmed.ncbi.nlm.nih.gov/32671230/)]

38. Bento AI, Nguyen T, Wing C, Lozano-Rojas F, Ahn Y, Simon K. Evidence from internet search data shows information-seeking responses to news of local COVID-19 cases. *Proc Natl Acad Sci U S A* 2020 May 26;117(21):11220-11222 [FREE Full text] [doi: [10.1073/pnas.2005335117](https://doi.org/10.1073/pnas.2005335117)] [Medline: [32366658](https://pubmed.ncbi.nlm.nih.gov/32366658/)]
39. Strzelecki A, Rizun M. Infodemiological Study Using Google Trends on Coronavirus Epidemic in Wuhan, China. *International Journal of Online and Biomedical Engineering* 2020 Apr 08;16(04):139-146. [doi: [10.3991/ijoe.v16i04.13531](https://doi.org/10.3991/ijoe.v16i04.13531)]
40. Effenberger M, Kronbichler A, Shin JI, Mayer G, Tilg H, Perco P. Association of the COVID-19 pandemic with Internet Search Volumes: A Google Trends Analysis. *Int J Infect Dis* 2020 Jun;95:192-197 [FREE Full text] [doi: [10.1016/j.ijid.2020.04.033](https://doi.org/10.1016/j.ijid.2020.04.033)] [Medline: [32305520](https://pubmed.ncbi.nlm.nih.gov/32305520/)]
41. Brodeur A, Clark AE, Fleche S, Powdthavee N. COVID-19, lockdowns and well-being: Evidence from Google Trends. *J Public Econ* 2021 Jan;193:104346 [FREE Full text] [doi: [10.1016/j.jpubeco.2020.104346](https://doi.org/10.1016/j.jpubeco.2020.104346)] [Medline: [33281237](https://pubmed.ncbi.nlm.nih.gov/33281237/)]
42. Tran US, Andel R, Niederkrotenthaler T, Till B, Ajdacic-Gross V, Voracek M. Low validity of Google Trends for behavioral forecasting of national suicide rates. *PLoS One* 2017 Aug 16;12(8):e0183149 [FREE Full text] [doi: [10.1371/journal.pone.0183149](https://doi.org/10.1371/journal.pone.0183149)] [Medline: [28813490](https://pubmed.ncbi.nlm.nih.gov/28813490/)]
43. Lee JY. Search trends preceding increases in suicide: A cross-correlation study of monthly Google search volume and suicide rate using transfer function models. *J Affect Disord* 2020 Feb 01;262:155-164. [doi: [10.1016/j.jad.2019.11.014](https://doi.org/10.1016/j.jad.2019.11.014)] [Medline: [31733460](https://pubmed.ncbi.nlm.nih.gov/31733460/)]
44. Holmes EA, O'Connor RC, Perry VH, Tracey I, Wessely S, Arseneault L, et al. Multidisciplinary research priorities for the COVID-19 pandemic: a call for action for mental health science. *Lancet Psychiatry* 2020 Jun;7(6):547-560 [FREE Full text] [doi: [10.1016/S2215-0366\(20\)30168-1](https://doi.org/10.1016/S2215-0366(20)30168-1)] [Medline: [32304649](https://pubmed.ncbi.nlm.nih.gov/32304649/)]

Abbreviations

WHO: World Health Organization

Edited by G Eysenbach; submitted 02.10.20; peer-reviewed by Z Ren, A Costanza; comments to author 07.10.20; revised version received 28.10.20; accepted 14.12.20; published 30.12.20.

Please cite as:

Burnett D, Eapen V, Lin PI

Time Trends of the Public's Attention Toward Suicide During the COVID-19 Pandemic: Retrospective, Longitudinal Time-Series Study

JMIR Public Health Surveill 2020;6(4):e24694

URL: <http://publichealth.jmir.org/2020/4/e24694/>

doi: [10.2196/24694](https://doi.org/10.2196/24694)

PMID: [33326407](https://pubmed.ncbi.nlm.nih.gov/33326407/)

©Dayle Burnett, Valsamma Eapen, Ping-I Lin. Originally published in *JMIR Public Health and Surveillance* (<http://publichealth.jmir.org>), 30.12.2020. This is an open-access article distributed under the terms of the Creative Commons Attribution License (<https://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in *JMIR Public Health and Surveillance*, is properly cited. The complete bibliographic information, a link to the original publication on <http://publichealth.jmir.org>, as well as this copyright and license information must be included.

Original Paper

SARS-CoV-2 Testing Service Preferences of Adults in the United States: Discrete Choice Experiment

Rebecca Zimba¹, MHS; Sarah Kulkarni¹, MPH; Amanda Berry¹, MPH; William You¹, MSPH; Chloe Mirzayi¹, MPH; Drew Westmoreland¹, PhD; Angela Parcesepe^{2,3}, PhD; Levi Waldron^{1,4}, PhD; Madhura Rane¹, PhD; Shivani Kochhar¹, MSc; McKaylee Robertson¹, PhD; Andrew Maroko^{1,5}, PhD; Christian Grov^{1,6}, MPH, PhD; Denis Nash^{1,4}, MPH, PhD

¹Institute for Implementation Science in Population Health, City University of New York, New York, NY, United States

²The Carolina Population Center, University of North Carolina at Chapel Hill, Chapel Hill, NC, United States

³Department of Maternal and Child Health, Gillings School of Global Public Health, University of North Carolina at Chapel Hill, Chapel Hill, NC, United States

⁴Department of Epidemiology and Biostatistics, Graduate School of Public Health and Health Policy, City University of New York, New York, NY, United States

⁵Department of Environmental, Occupational, and Geospatial Health Sciences, Graduate School of Public Health and Health Policy, City University of New York, New York, NY, United States

⁶Department of Community Health and Social Sciences, Graduate School of Public Health and Health Policy, City University of New York, New York, NY, United States

Corresponding Author:

Rebecca Zimba, MHS

Institute for Implementation Science in Population Health

City University of New York

55 W 125th St, 6th Floor

New York, NY, 10027

United States

Phone: 1 646 364 9618

Email: rebecca.zimba@sph.cuny.edu

Abstract

Background: Ascertaining preferences for SARS-CoV-2 testing and incorporating findings into the design and implementation of strategies for delivering testing services may enhance testing uptake and engagement, a prerequisite to reducing onward transmission.

Objective: This study aims to determine important drivers of decisions to obtain a SARS-CoV-2 test in the context of increasing community transmission.

Methods: We used a discrete choice experiment to assess preferences for SARS-CoV-2 test type, specimen type, testing venue, and results turnaround time. Participants (n=4793) from the US national longitudinal Communities, Households and SARS-CoV-2 Epidemiology (CHASING) COVID Cohort Study completed our online survey from July 30 to September 8, 2020. We estimated the relative importance of testing method attributes and part-worth utilities of attribute levels, and simulated the uptake of an optimized testing scenario relative to the current typical testing scenario of polymerase chain reaction (PCR) via nasopharyngeal swab in a provider's office or urgent care clinic with results in >5 days.

Results: Test result turnaround time had the highest relative importance (30.4%), followed by test type (28.3%), specimen type (26.2%), and venue (15.0%). In simulations, immediate or same-day test results, both PCR and serology, or oral specimens substantially increased testing uptake over the current typical testing option. Simulated uptake of a hypothetical testing scenario of PCR and serology via a saliva sample at a pharmacy with same-day results was 97.7%, compared to 0.6% for the current typical testing scenario, with 1.8% opting for no test.

Conclusions: Testing strategies that offer both PCR and serology with noninvasive methods and rapid turnaround time would likely have the most uptake and engagement among residents in communities with increasing community transmission of SARS-CoV-2.

(*JMIR Public Health Surveill* 2020;6(4):e25546) doi:[10.2196/25546](https://doi.org/10.2196/25546)

KEYWORDS

COVID-19; SARS-CoV-2; discrete choice experiment; implementation science; engagement; testing; cohort study; stated preference study; pandemic

Introduction

The Centers for Disease Control and Prevention recently estimated that for every case of SARS-CoV-2 infection diagnosed in the United States, an additional 10 are undiagnosed [1]. Detecting a higher proportion of people with active infection via widespread testing is a prerequisite to achieving the public health goals of controlling the transmission of SARS-CoV-2 [2,3]. However, limited access to and uptake of testing for many in the United States, combined with lengthy result turnaround time, severely hampers pandemic control efforts, which require timely detection, isolation, and quarantine. Although recent increases in testing are promising [4], some models [5] suggest a shortfall, and important populations may still be unreached [6]. Understanding factors that may influence an individual's decision to seek testing can help enhance and sustain uptake of SARS-CoV-2 testing when, where, and among whom it is needed most for public health purposes. These factors include individual preferences for different types of testing services, which have not been systematically ascertained or incorporated into testing service delivery.

Methods

To identify the most preferred SARS-CoV-2 testing scenarios for individuals, we conducted a discrete choice experiment (DCE) [7,8] in a US national longitudinal cohort of adults being followed for SARS-CoV-2 seroconversion and other related outcomes. DCEs are a powerful tool to identify the most preferred attributes in populations being targeted for health interventions and can inform strategies to increase interventions' uptake and engagement.

Study Population

We invited all participants of the Communities, Households and SARS-CoV-2 Epidemiology (CHASING) COVID Cohort Study [9] who completed a recent routine follow-up assessment ($n=5098$) to participate in the DCE. CHASING COVID Cohort Study participants were recruited online using internet-based strategies, including via referral, social media advertisements in English and Spanish, and Qualtrics Panel [9]. Recruitment and advertising strategies were periodically adjusted to increase diversity across racial, ethnic, and age groups. Eligibility criteria included being 18 years or older and residing in the United States, Puerto Rico, or Guam at enrollment. Participants provided informed consent at the baseline assessment and separately for SARS-CoV-2 antibody testing. A total of 4793 (94% of those invited) completed the DCE July 30 to September 8, 2020. A US \$5 Amazon gift card incentive was offered to participants completing the DCE.

DCE Design, Analysis, and Simulation

The DCE was designed and implemented using Lighthouse Studio 9.8.1 (Sawtooth Software) and deployed using Sawtooth's online survey hosting platform. Participants were asked to consider different combinations of SARS-CoV-2 testing service features in a situation where "...the number of people hospitalized or dying from coronavirus in your community was increasing." Each participant was presented with five choice tasks, each containing two juxtaposed scenarios comprised of different combinations of the testing features (aka attribute levels) and a "None" option if neither testing scenario was appealing or desirable. Testing service attributes included in the DCE are shown in Table 1 and included: type of test, specimen type, testing venue, and results turnaround time (see also Multimedia Appendix 1). The combinations presented and the order of their presentation to each participant were randomized to reduce bias (see Multimedia Appendix 2).

We estimated zero-centered part-worth utilities for each attribute level and overall relative attribute importance using effects coding in a hierarchical Bayesian model [10]. We used these estimates to simulate changes in uptake of the different testing scenarios that resulted from "swapping" each individual attribute level in Table 1 into the current typical testing option of a polymerase chain reaction (PCR) test using a nasopharyngeal (NP) swab in a doctor's office or urgent care clinic, with results returned in >5 days. The baseline simulation contained three scenarios: (1) the primary current typical testing scenario; (2) a second, duplicate current typical testing scenario; and (3) a no test scenario. Each attribute level was then individually varied in the duplicated scenario, holding all levels in the other attributes in the duplicated scenario constant. The uptake of each varied scenario was simulated along with the two other original scenarios, and the uptake of the modified scenario was compared to the uptake of the primary current typical testing scenario in the baseline simulation.

We also created a hypothetical testing scenario that optimized preferences across attributes, which included PCR and serology from a saliva sample collected at a pharmacy with same-day results. We then simulated the proportion of participants who would choose this optimized scenario, the current typical testing option, or neither option. For all simulations, predicted uptake of each testing strategy was estimated using the randomized first choice method [11,12], which computes the proportion of participants that would choose each testing scenario based on its total utility, over thousands of draws per participant, assuming that each participant would select the scenario that provides them with the highest total utility summed across attributes. DCE data were analyzed and simulations were conducted using Lighthouse Studio 9.8.1.

Table 1. SARS-CoV-2 testing discrete choice experiment attributes and levels.

Attributes and levels (abbreviated) ^a	Descriptive-level text ^b
Test	
Serology	An antibody test that tells you if you've EVER had a COVID-19 infection
PCR ^c	A PCR test that tells you if you CURRENTLY have a COVID-19 infection
Both tests	BOTH an antibody test (EVER infected) and a PCR test (CURRENTLY infected)
Specimen type	
Finger prick	A small amount of blood from a finger prick
Blood draw	A small tube of blood taken from your arm
Cheek	Oral fluid from a swab of the inside of your cheek
Spit	A spit sample collected in a small cup
Nasal shallow	A SHALLOW swab of the inside of your nostrils
NP ^d swab	A DEEP swab that goes far into your nasal passages
Urine	A urine sample collected in a small cup
Venue	
Home collection, receiving, and returning kit in mail	You are mailed a package with the test kit; you collect the specimen and mail it back to the lab
Home collection, receiving kit in mail, and returning to a collection site	You are mailed a package with the test kit; you collect the specimen and drop it off at a collection site near your home
Doctor's office or urgent care clinic	You go to your doctor's office or an urgent care clinic to have the specimen collected
Walk-in community testing site	You go to a walk-in community testing site to have the specimen collected
Drive-through community testing site	You go to a drive-through community testing site to have the specimen collected (you stay in your car)
Pharmacy	You go to a local pharmacy to have the specimen collected
Results turnaround time	
Immediate	Immediately (within 15 minutes)
Same day	On the same day
48 hours	Within 48 hours
5 days	Within 5 days
Greater than 5 days	>5 days

^aSome combinations of attribute levels were prohibited. For example, a test scenario that included a specimen collected at home and returned to the lab via mail could not also include the immediate test result level.

^bDescriptive text was displayed in the choice exercise.

^cPCR: polymerase chain reaction.

^dNP: nasopharyngeal.

Ethical Review

This study was approved by the Institutional Review Board at the City University of New York (CUNY) Graduate School of Public Health.

Results

Participant Demographic Characteristics

Participants' median age was 39 (IQR 30-53) years. Out of the 4793 participants, 51.5% (n=2468) identified as female, 45.8% (n=2193) identified as male, and 2.8% (n=132) identified as other gender identities (nonbinary, transgender male, transgender

female). Additionally, 62.8% (n=3009) identified as non-Hispanic White, 16.4% (n=788) identified as Hispanic, 9.2% (n=442) identified as non-Hispanic Black, 7.5% (n=361) identified as Asian, 3.9% (n=189) identified as another race or ethnicity, and 0.1% (n=4) had missing information for race and ethnicity. At enrollment, 29.0% (n=1391) of participants resided in the Northeast, 28.3% (n=1358) resided in the South, 23.9% (n=1146) resided in the West, 17.7% (n=850) resided in the Midwest, and 0.2% (n=7) resided in Puerto Rico or Guam; 0.9% (n=41) of participants affirmed US residence but did not provide a zip code with which to assign them a region.

Relative Importance of Testing Service Attributes and Attribute Levels

Results turnaround time had the highest relative importance (30.4%), followed by test type (28.3%), specimen type (26.2%), and venue (15.0%; see Table S1 in [Multimedia Appendix 3](#)). Participants strongly preferred rapid receipt of results, with progressively weaker preference for slower test results. Within test type, participants showed a strong preference for testing scenarios that detect both current and past infection (see Table S2 in [Multimedia Appendix 3](#)). Participants most preferred testing scenarios that use cheek swab specimens and least preferred scenarios that require a deep NP swab. There was a preference for at-home self-collection of specimens using kits received and returned via mail; testing in a doctor’s office or urgent care clinic was the least preferred testing venue. Participants chose neither testing option in only 3.6% (861/23,965) of the choice tasks.

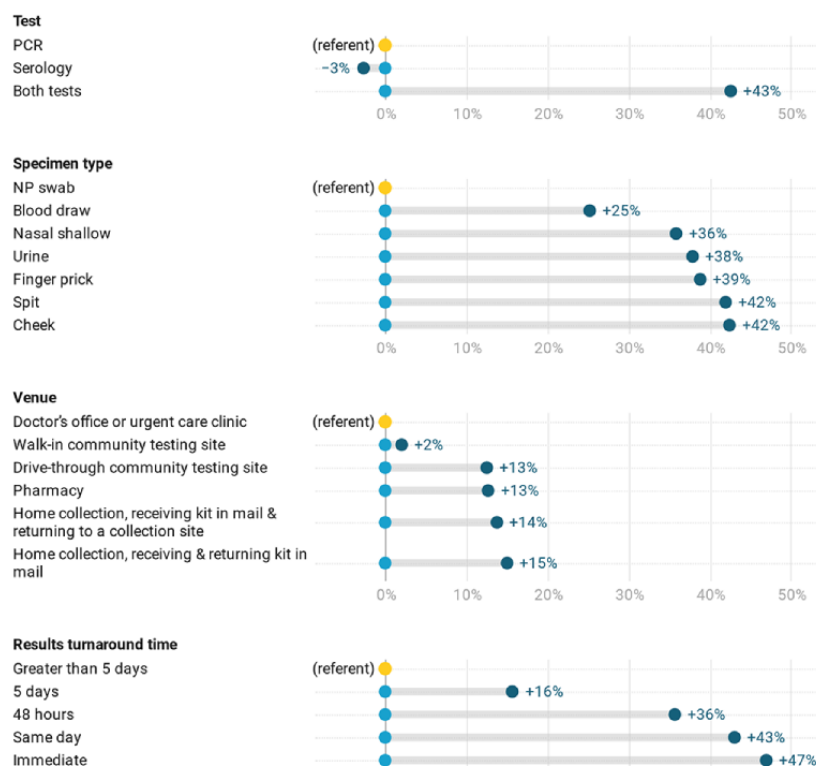
Simulation Results

Simulating changes in SARS-CoV-2 testing uptake by varying attribute levels individually, we found the largest marginal increases in testing uptake from including immediate test results (+47%) or same-day test results (+43%), with more modest increases for results 48 hours after the test (+36%) and 5 days

after the test (+16%), compared to results in >5 days (see [Figure 1](#)). Testing scenarios that offered both PCR and serology also substantially increased marginal uptake (+43%), whereas serology testing alone slightly decreased uptake (–3%). Among specimen types, oral specimens (cheek or spit [+42%]) had the largest increase in uptake over NP swab, followed by finger prick (+39%), urine (+38%), shallow nasal swab (+36%), and blood draw (+25%). Though smaller in magnitude, we found increases in uptake for testing venue alternatives to a doctor’s office or urgent care clinic, with the greatest increases for the home testing venues (receiving and returning the test kit in the mail [+15%] and receiving the kit in the mail and returning to a collection site [+14%]), followed by pharmacy (+13%), drive-through community testing site (+13%), and walk-in community testing site (+2%).

We also simulated the proportion of participants that would pick the current typical testing scenario versus a scenario with multiple more preferable features: both PCR and serology using a saliva specimen collected at a pharmacy with same-day test results. Simulated uptake of this hypothetical scenario was 97.7% compared to 0.6% for the current typical testing scenario, with 1.8% opting for no test when presented with these two choices.

Figure 1. Simulated changes in SARS-CoV-2 testing uptake relative to the current typical testing option, by attribute level. The current typical testing option is PCR via NP swab in a provider’s office or urgent care clinic with results in >5 days. The baseline simulation included the current typical testing option compared to a second duplicate current typical testing scenario and a no test scenario. Changes in uptake in subsequent simulations were estimated by individually varying each attribute level in the duplicated scenario, holding other attributes constant. The referent value of zero is the difference between the original and duplicated typical testing scenarios at baseline. NP: nasopharyngeal; PCR: polymerase chain reaction.



Discussion

Principal Results

Our participants preferred faster test results from less invasive specimens collected at home that provide comprehensive information about current and past infection. From a public health perspective, faster test results are more actionable [13], and at the individual level, delayed test results can provoke anxiety in other diagnostic settings [14-16]. Participants tended to favor specimen collection venues that could be construed as more convenient (pharmacy or drive-through testing site) or better able to facilitate social distancing (home), compared to a walk-in clinic or doctor's office, where one might be more likely to come into contact with infectious individuals. Our venue-related results are in line with findings from the HIV and sexually transmitted infection literature, where at-home specimen collection for diagnostic testing has high acceptability and reliability [17,18], and with other recent findings indicating high willingness to collect at-home specimens for a SARS-CoV-2 research study [19]. The strong preference for both PCR and serology may be related to a belief that antibodies confer immunity against subsequent infection [20,21] and a general desire to get the most utility out of a single specimen.

Our findings suggest that expected advances in SARS-CoV-2 testing technologies, such as rapid, at-home saliva tests, will be highly acceptable and used when they become available, particularly in communities with increasing deaths or hospitalizations. Some preferred tests for SARS-CoV-2 (eg,

at-home rapid antigen tests) may be less sensitive than gold standard diagnostic tests (PCR via NP swab). Nevertheless, these findings are significant from a public health standpoint since it's possible that widespread and frequent use of a less sensitive SARS-CoV-2 antigen test could detect much greater numbers of people with active infection—and more quickly—than the current typical testing scenario [22]. Indeed, our data suggest that NP swabs may be a deterrent to testing, which could be addressed by adding serology or relying on saliva specimens.

Limitations

Limitations of this study include the omission of other attributes that may influence testing preferences, such as frequency of testing, cost, facility wait times, or distance. In addition, the majority of our participants had already completed at-home self-collection of a dried blood spot specimen for our study. Though the venue attribute had the lowest relative importance, this prior experience may have influenced their preferences for venue in the DCE.

Conclusions

To the extent that it is possible to align public health strategies to deliver testing services with the preferences of those being targeted for testing, greater uptake and engagement may be achieved. Additional research is needed to increase SARS-CoV-2 testing uptake in ways that are aligned with the public health goals of the pandemic response, including preferences for engaging in public health interventions following a positive test, such as isolation and contact tracing [3].

Acknowledgments

This study was supported by the CUNY Institute for Implementation Science in Population Health (DN), the COVID-19 Grant Program of the CUNY Graduate School of Public Health and Health Policy (DN), the National Institute of Allergy and Infectious Diseases of the National Institutes of Health under Award Number UH3AI133675 (DN and CG), and the Eunice Kennedy Shriver National Institute of Child Health and Human Development under Award Number P2C HD050924 (AP, The Carolina Population Center).

We would like to acknowledge the CHASING COVID Cohort Study participants for their contributions to this research.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Desktop example of SARS-CoV-2 testing preferences choice task.

[[DOCX File , 254 KB - publichealth_v6i4e25546_app1.docx](#)]

Multimedia Appendix 2

Supplementary methods.

[[DOCX File , 13 KB - publichealth_v6i4e25546_app2.docx](#)]

Multimedia Appendix 3

Table S1 (average relative attribute importance for SARS-CoV-2 testing features) and Table S2 (part-worth utilities for SARS-CoV-2 testing features).

[[DOCX File , 18 KB - publichealth_v6i4e25546_app3.docx](#)]

References

1. Havers FP, Reed C, Lim T, Montgomery JM, Klena JD, Hall AJ, et al. Seroprevalence of antibodies to SARS-CoV-2 in 10 sites in the United States, March 23-May 12, 2020. *JAMA Intern Med* 2020 Jul 21. [doi: [10.1001/jamainternmed.2020.4130](https://doi.org/10.1001/jamainternmed.2020.4130)] [Medline: [32692365](https://pubmed.ncbi.nlm.nih.gov/32692365/)]
2. Giordano G, Blanchini F, Bruno R, Colaneri P, Di Filippo A, Di Matteo A, et al. Modelling the COVID-19 epidemic and implementation of population-wide interventions in Italy. *Nat Med* 2020 Jun;26(6):855-860 [FREE Full text] [doi: [10.1038/s41591-020-0883-7](https://doi.org/10.1038/s41591-020-0883-7)] [Medline: [32322102](https://pubmed.ncbi.nlm.nih.gov/32322102/)]
3. Nash D, Geng E. Goal-aligned, epidemic intelligence for the public health response to the COVID-19 pandemic. *Am J Public Health* 2020 Aug;110(8):1154-1156. [doi: [10.2105/AJPH.2020.305794](https://doi.org/10.2105/AJPH.2020.305794)] [Medline: [32614614](https://pubmed.ncbi.nlm.nih.gov/32614614/)]
4. New tests (total test results). COVID Tracking Project at the Atlantic. 2020. URL: <https://covidtracking.com/data> [accessed 2020-09-09]
5. Kates J, Michaud J, Orgera K, Levitt L. What testing capacity do we need? Kaiser Family Foundation. 2020 Apr 17. URL: <https://www.kff.org/policy-watch/what-testing-capacity-do-we-need/> [accessed 2020-09-09]
6. Tromberg BJ, Schwetz TA, Pérez-Stable EJ, Hodes RJ, Woychik RP, Bright RA, et al. Rapid scaling up of Covid-19 diagnostic testing in the United States - The NIH RADx Initiative. *N Engl J Med* 2020 Sep 10;383(11):1071-1077 [FREE Full text] [doi: [10.1056/NEJMsr2022263](https://doi.org/10.1056/NEJMsr2022263)] [Medline: [32706958](https://pubmed.ncbi.nlm.nih.gov/32706958/)]
7. Ryan M, Farrar S. Using conjoint analysis to elicit preferences for health care. *BMJ* 2000 Jun 03;320(7248):1530-1533 [FREE Full text] [doi: [10.1136/bmj.320.7248.1530](https://doi.org/10.1136/bmj.320.7248.1530)] [Medline: [10834905](https://pubmed.ncbi.nlm.nih.gov/10834905/)]
8. Reed Johnson F, Lancsar E, Marshall D, Kilambi V, Mühlbacher A, Regier DA, et al. Constructing experimental designs for discrete-choice experiments: report of the ISPOR Conjoint Analysis Experimental Design Good Research Practices Task Force. *Value Health* 2013;16(1):3-13 [FREE Full text] [doi: [10.1016/j.jval.2012.08.2223](https://doi.org/10.1016/j.jval.2012.08.2223)] [Medline: [23337210](https://pubmed.ncbi.nlm.nih.gov/23337210/)]
9. Robertson M, Kulkarni S, Berry A, Mirzayi C, Maroko A, Zimba R, et al. A national prospective cohort study of SARS/COV2 pandemic outcomes in the U.S.: The CHASING COVID Cohort. medRxiv. Preprint posted online May 4, 2020 [FREE Full text] [doi: [10.1101/2020.04.28.20080630](https://doi.org/10.1101/2020.04.28.20080630)]
10. Hauber AB, González JM, Groothuis-Oudshoorn CGM, Prior T, Marshall DA, Cunningham C, et al. Statistical methods for the analysis of discrete choice experiments: a report of the ISPOR Conjoint Analysis Good Research Practices Task Force. *Value Health* 2016 Jun;19(4):300-315 [FREE Full text] [doi: [10.1016/j.jval.2016.04.004](https://doi.org/10.1016/j.jval.2016.04.004)] [Medline: [27325321](https://pubmed.ncbi.nlm.nih.gov/27325321/)]
11. Randomized first choice. Sawtooth Software. URL: https://sawtoothsoftware.com/help/lighthouse-studio/manual/hid_randomizedfirstchoice.html [accessed 2020-08-21]
12. Orme B. Getting Started with Conjoint Analysis. Manhattan Beach, CA: Research Publishers, LLC; 2014.
13. Kretzschmar ME, Rozhnova G, Bootsma MCJ, van Boven M, van de Wijgert JHHM, Bonten MJM. Impact of delays on effectiveness of contact tracing strategies for COVID-19: a modelling study. *Lancet Public Health* 2020 Aug;5(8):e452-e459 [FREE Full text] [doi: [10.1016/S2468-2667\(20\)30157-2](https://doi.org/10.1016/S2468-2667(20)30157-2)] [Medline: [32682487](https://pubmed.ncbi.nlm.nih.gov/32682487/)]
14. Lang EV, Berbaum KS, Lutgendorf SK. Large-core breast biopsy: abnormal salivary cortisol profiles associated with uncertainty of diagnosis. *Radiology* 2009 Mar;250(3):631-637. [doi: [10.1148/radiol.2503081087](https://doi.org/10.1148/radiol.2503081087)] [Medline: [19244038](https://pubmed.ncbi.nlm.nih.gov/19244038/)]
15. Bennett P, Phelps C, Brain K, Hood K, Gray J. A randomized controlled trial of a brief self-help coping intervention designed to reduce distress when awaiting genetic risk information. *J Psychosom Res* 2007 Jul;63(1):59-64. [doi: [10.1016/j.jpsychores.2007.01.016](https://doi.org/10.1016/j.jpsychores.2007.01.016)] [Medline: [17586338](https://pubmed.ncbi.nlm.nih.gov/17586338/)]
16. Lerman C, Croyle RT, Tercyak KP, Hamann H. Genetic testing: psychological aspects and implications. *J Consult Clin Psychol* 2002 Jun;70(3):784-797. [doi: [10.1037//0022-006x.70.3.784](https://doi.org/10.1037//0022-006x.70.3.784)] [Medline: [12090383](https://pubmed.ncbi.nlm.nih.gov/12090383/)]
17. Pearson WS, Kreisel K, Peterman TA, Zlotorzynska M, Dittus PJ, Habel MA, et al. Improving STD service delivery: would American patients and providers use self-tests for gonorrhea and chlamydia? *Prev Med* 2018 Oct;115:26-30. [doi: [10.1016/j.ypmed.2018.08.007](https://doi.org/10.1016/j.ypmed.2018.08.007)] [Medline: [30096329](https://pubmed.ncbi.nlm.nih.gov/30096329/)]
18. Figueroa C, Johnson C, Ford N, Sands A, Dalal S, Meurant R, et al. Reliability of HIV rapid diagnostic tests for self-testing compared with testing by health-care workers: a systematic review and meta-analysis. *Lancet HIV* 2018 Jun;5(6):e277-e290 [FREE Full text] [doi: [10.1016/S2352-3018\(18\)30044-4](https://doi.org/10.1016/S2352-3018(18)30044-4)] [Medline: [29703707](https://pubmed.ncbi.nlm.nih.gov/29703707/)]
19. Hall EW, Luisi N, Zlotorzynska M, Wilde G, Sullivan P, Sanchez T, et al. Willingness to use home collection methods to provide specimens for SARS-CoV-2/COVID-19 research: survey study. *J Med Internet Res* 2020 Sep 03;22(9):e19471 [FREE Full text] [doi: [10.2196/19471](https://doi.org/10.2196/19471)] [Medline: [32790639](https://pubmed.ncbi.nlm.nih.gov/32790639/)]
20. Spellberg B, Nielsen TB, Casadevall A. Antibodies, immunity, and COVID-19. *JAMA Intern Med* 2020 Nov 24. [doi: [10.1001/jamainternmed.2020.7986](https://doi.org/10.1001/jamainternmed.2020.7986)] [Medline: [33231673](https://pubmed.ncbi.nlm.nih.gov/33231673/)]
21. Overview of testing for SARS-CoV-2 (COVID-19). Centers for Disease Control and Prevention. URL: <https://www.cdc.gov/coronavirus/2019-ncov/hcp/testing-overview.html> [accessed 2020-10-18]
22. Larremore DB, Wilder B, Lester E, Shehata S, Burke JM, Hay JA, et al. Test sensitivity is secondary to frequency and turnaround time for COVID-19 screening. *Sci Adv* 2020 Nov 20. [doi: [10.1126/sciadv.abd5393](https://doi.org/10.1126/sciadv.abd5393)] [Medline: [33219112](https://pubmed.ncbi.nlm.nih.gov/33219112/)]

Abbreviations

CHASING: Communities, Households and SARS-CoV-2 Epidemiology

CUNY: City University of New York

DCE: discrete choice experiment

NP: nasopharyngeal

PCR: polymerase chain reaction

Edited by Y Khader; submitted 05.11.20; peer-reviewed by E Geng, R Krukowski; comments to author 02.12.20; revised version received 09.12.20; accepted 09.12.20; published 31.12.20.

Please cite as:

Zimba R, Kulkarni S, Berry A, You W, Mirzayi C, Westmoreland D, Parcesepe A, Waldron L, Rane M, Kochhar S, Robertson M, Maroko A, Grov C, Nash D

SARS-CoV-2 Testing Service Preferences of Adults in the United States: Discrete Choice Experiment

JMIR Public Health Surveill 2020;6(4):e25546

URL: <http://publichealth.jmir.org/2020/4/e25546/>

doi: [10.2196/25546](https://doi.org/10.2196/25546)

PMID: [33315584](https://pubmed.ncbi.nlm.nih.gov/33315584/)

©Rebecca Zimba, Sarah Kulkarni, Amanda Berry, William You, Chloe Mirzayi, Drew Westmoreland, Angela Parcesepe, Levi Waldron, Madhura Rane, Shivani Kochhar, McKaylee Robertson, Andrew Maroko, Christian Grov, Denis Nash. Originally published in JMIR Public Health and Surveillance (<http://publichealth.jmir.org>), 31.12.2020. This is an open-access article distributed under the terms of the Creative Commons Attribution License (<https://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in JMIR Public Health and Surveillance, is properly cited. The complete bibliographic information, a link to the original publication on <http://publichealth.jmir.org>, as well as this copyright and license information must be included.

Original Paper

A Racially Unbiased, Machine Learning Approach to Prediction of Mortality: Algorithm Development Study

Angier Allen¹, MA; Samson Mataraso¹, BS; Anna Siefkas¹, SM; Hoyt Burdick^{2,3}, MD; Gregory Braden⁴, MD; R Phillip Dellinger⁵, MD; Andrea McCoy⁶, MD; Emily Pellegrini¹, MEng; Jana Hoffman¹, PhD; Abigail Green-Saxena¹, PhD; Gina Barnes¹, MPH; Jacob Calvert¹, MSc; Ritankar Das¹, MSc

¹Dascena, Inc, San Francisco, CA, United States

²Cabell Huntington Hospital, Huntington, WV, United States

³Marshall University School of Medicine, Huntington, WV, United States

⁴Kidney Care and Transplant Associates of New England, Springfield, MA, United States

⁵Division of Critical Care Medicine, Cooper University Hospital/Cooper Medical School of Rowan University, Camden, NJ, United States

⁶Cape Regional Medical Center, Cape May Court House, NJ, United States

Corresponding Author:

Anna Siefkas, SM

Dascena, Inc

PO Box 156572

San Francisco, CA

United States

Phone: 1 510 826 950

Email: anna@dascena.com

Abstract

Background: Racial disparities in health care are well documented in the United States. As machine learning methods become more common in health care settings, it is important to ensure that these methods do not contribute to racial disparities through biased predictions or differential accuracy across racial groups.

Objective: The goal of the research was to assess a machine learning algorithm intentionally developed to minimize bias in in-hospital mortality predictions between white and nonwhite patient groups.

Methods: Bias was minimized through preprocessing of algorithm training data. We performed a retrospective analysis of electronic health record data from patients admitted to the intensive care unit (ICU) at a large academic health center between 2001 and 2012, drawing data from the Medical Information Mart for Intensive Care-III database. Patients were included if they had at least 10 hours of available measurements after ICU admission, had at least one of every measurement used for model prediction, and had recorded race/ethnicity data. Bias was assessed through the equal opportunity difference. Model performance in terms of bias and accuracy was compared with the Modified Early Warning Score (MEWS), the Simplified Acute Physiology Score II (SAPS II), and the Acute Physiologic Assessment and Chronic Health Evaluation (APACHE).

Results: The machine learning algorithm was found to be more accurate than all comparators, with a higher sensitivity, specificity, and area under the receiver operating characteristic. The machine learning algorithm was found to be unbiased (equal opportunity difference 0.016, $P=.20$). APACHE was also found to be unbiased (equal opportunity difference 0.019, $P=.11$), while SAPS II and MEWS were found to have significant bias (equal opportunity difference 0.038, $P=.006$ and equal opportunity difference 0.074, $P<.001$, respectively).

Conclusions: This study indicates there may be significant racial bias in commonly used severity scoring systems and that machine learning algorithms may reduce bias while improving on the accuracy of these methods.

(*JMIR Public Health Surveill* 2020;6(4):e22400) doi:[10.2196/22400](https://doi.org/10.2196/22400)

KEYWORDS

machine learning; health disparities; racial disparities; mortality; prediction

Introduction

Health care disparities are well documented in the United States [1]. These disparities affect the accessibility of care, quality of care, and health outcomes of racial minority groups [1-4]. Causes of these inequities are multifaceted and include socioeconomic factors, institutionalized racism, and a historically motivated lack of trust between minority populations and health care providers [1,5,6].

Technology can play a powerful role toward the effort of both exposing and minimizing disparities in health care. In particular, artificial intelligence (AI) and machine learning approaches have the potential to either maintain or reduce systemic inequities in health care settings and outcomes. Much attention has been given to the fact that AI and machine learning systems trained on data that reflects racial disparities will in turn learn and perpetuate such disparities and their influence on the health care system [7]. Several studies have found evidence that machine learning-based algorithms commonly used in health care settings exhibit differential accuracy by race [8,9]. A recent study by Vyas et al [10] found that algorithms used across a broad range of specialties, including cardiology, urology, and oncology, may exhibit differential accuracy across race even after so-called race corrections. By attempting to correct for race, these tools may in fact make it more difficult for nonwhite patients to receive appropriate care. For example, the authors note that these corrections move black patients systematically toward lower risk scores when computing cardiac mortality risk [11] and estimated kidney function [12], while deeming nonwhite patients higher risks for complications for procedures such as vaginal birth following a cesarean delivery [13] and certain cardiac surgeries [14]. Vyas et al [10] conclude that the use of these race-corrected tools may not only impact the quality and timeliness of care that nonwhite patients receive but may also enshrine certain racial disparities as fact, making disparities more difficult to minimize.

Despite the potential for bias found in specialized scoring systems, insufficient attention has yet been paid to how early warning scores and mortality scores intended for the general patient population may similarly perpetuate racial disparities in health outcomes. Many studies on the development and validation of scoring systems such as the Modified Early Warning Score (MEWS) [15] report findings from predominantly white patient samples [16] or do not report race data at all [15,17,18]. Literature directly examining the potential for racial bias in these scoring systems has found evidence of differential performance by race. Several studies of the emergency severity index (ESI) [19] have found systematic underestimation of acuity scores for nonwhite patients in general [20], pediatric [21], and veteran populations [22] when controlling for a wide range of important confounders. Similarly,

a study of MEWS performance in an Asian population found reduced accuracy as compared with validation studies performed on predominantly white samples [23]. These findings have wide ranging implications and suggest the use of such scores may accentuate health disparities wherever they are used. Pressingly, their use in triaging patients during the COVID-19 crisis may contribute to disparities in COVID-19 outcomes.

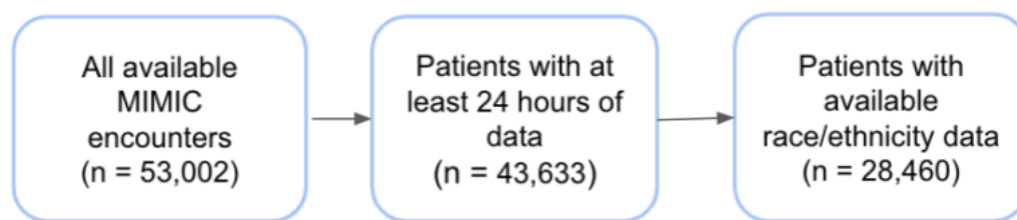
To address this issue, we have developed a machine learning algorithm for the prediction of patient mortality [24], designed to minimize the potential for racial bias in algorithm prediction scores. We compare this algorithm performance to commonly used patient severity scoring systems, including MEWS, the Simplified Acute Physiology Score II (SAPS II) [25], and the Acute Physiologic Assessment and Chronic Health Evaluation (APACHE) [26] score across white and nonwhite racial groups. This study aims to determine whether a machine learning algorithm can minimize racial bias in patient risk predictions as compared with commonly used rules-based methods.

Methods

Data Processing

Data were drawn from the Medical Information Mart for Intensive Care-III (MIMIC-III) database [27]. The database consists of data on more than 53,000 patient encounters for patients admitted to the intensive care unit at a large academic health center between 2001 and 2012. Patients were included if they had at least 10 hours of available measurements after intensive care unit (ICU) admission, had at least one of every measurement used for model prediction, and had recorded race/ethnicity data. Patients for whom race/ethnicity was missing or recorded as declined to state or unknown were considered to have no available race/ethnicity data. Patient inclusion is shown in Figure 1. In assessing the potential for differential performance across racial groups, patients were grouped as non-Hispanic white or nonwhite.

Data were extracted on age and 13 commonly used patient measurements, including diastolic blood pressure, systolic blood pressure, heart rate, temperature, respiratory rate, oxygen saturation, white blood cell, platelets, creatinine, Glasgow coma scale, fraction of inspired oxygen, and potassium and sodium levels. Data on each measure were gathered hourly for 10 hours, beginning at the time of ICU admission. If multiple values of a single measure were recorded during a given hour, their average was taken and used. Not all measures were available for all patients. Outliers in the data, defined as being above the 99th or below the 1st percentile for the given feature, were deleted and marked as missing. The algorithm is capable of making predictions in the presence of missing data. When calculating the tabular scores for the comparators, missing values added 0 points towards the total score.

Figure 1. Attrition diagram for patient inclusion.

Machine Learning Model

The machine learning mortality predictor was developed using XGBoost [28], a gradient boosting technique. Gradient boosting combines results from multiple decision trees, where each decision tree divides patients into successively smaller groups based on their vital sign values. For example, one branch of a decision tree might divide patients into two groups depending on if their heart rate was over or under 90 beats per minute. Each tree ends in a set of leaves, where each patient is represented in a single leaf based on their set of measurements. The particular leaf to which the patient is sent on each decision tree yields a risk score. The score from each tree is then weighted and totaled to give the model's final prediction for the specified patient. A variety of parameter combinations controlling tree depth and maximum weights assigned to each leaf were used to identify the best performing model.

To train the model to make mortality predictions without discrimination, we preprocessed our training data in two steps. These steps were performed with the intention of removing aspects of the data that reflect systemic inequities in health across racial groups while maintaining the aspects of the data that reflected relevant patient measurements and outcomes. First, the patients were separated into age groups defined as younger than 18 years, 18 to 29 years, 30 to 39 years, 40 to 49 years, 50 to 59 years, 60 to 69 years, and 70 years and older. This was to control for the high correlation between age and mortality rate. Second, individual training examples were given weights based on mortality status and race within each age strata using a reweighting scheme. This was done by weighting each training example in the following way: first the expected probability of observing the given combination of race and mortality was calculated by assuming statistical independence of these variables. This was then compared with the observed probability of the variable combination found in the training data. This ratio of expected to observed probability was then used as the weight for each training example. This ratio can be considered a demographic prevalence ratio and is based on the method originally described by Kamarin and Calders [7]. Example code for this preprocessing method is included in [Multimedia Appendix 1](#).

To train and test the machine learning algorithm, we used 10-fold cross-validation. Reported performance metrics are an average of each model's performance on each of the 10 test sets. Several baseline models were assessed as candidates for development. We compared the performance of gradient-boosted trees (using XGBoost), logistic regression, and multilayer perceptron models for mortality prediction. We found that gradient-boosted trees performed best at baseline and chose

them as the primary model type on which to perform all subsequent experiments. Pairwise comparisons between gradient-boosted trees and alternative model types without preprocessing were made using a Student *t* test for area under the receiver operating characteristic (AUROC) and the McNemar test for distinguishing predictions.

Statistical Analysis

The predictive performance of all comparators was assessed by associating each comparator score with the mortality rate found in training encounters that had the same score. In addition, the highest probability observed for a score was carried forward to the next score value if it was found to have a lower probability of death to ensure increasing scores were monotonically associated with an increased probability of the outcome. Comparator scores were assessed on each of the 10 folds used in cross-fold model validation.

For all models, predictions were made after 24 hours of ICU data were collected, with the mortality outcome defined as any in-hospital mortality at end of stay. Overall predictive performance of comparators and the machine learning algorithm are reported using the area under the receiver operating characteristic, sensitivity, specificity, diagnostic odds ratio (DOR), and positive and negative likelihood ratios (LR+ and LR-).

To assess whether the machine learning algorithm and each comparator identified similar at-risk individuals, the McNemar test was used, comparing performance of the two systems at a sensitivity around 0.75. Performance was assessed both on the overall sample and after stratifying by race. Racial categories were defined as white and nonwhite, where only non-Hispanic white patients were included in the white category (eg, a white Hispanic patient was considered nonwhite for the purpose of this analysis).

Model bias was assessed using the equal opportunity difference statistic. Equal opportunity difference measures the distribution of false negative results across two groups produced by each prediction method and assesses the difference in the false negative rate between the groups. False negative results are of particular importance for mortality prediction tools as a failure to provide an alert for a patient at risk of mortality may lead to a lack of timely care and an increased risk of death. Under an unbiased predictor, the false negative rate should not differ between the racial groups; the expected value of the equal opportunity difference statistic for an unbiased predictor is therefore 0. Significance of the equal opportunity difference statistic was assessed using a Student *t* test under the null hypothesis that the equal opportunity difference was equal to 0. Equal opportunity difference statistics were assessed

separately for all prediction models. For all statistical tests, an alpha of .05 was used.

The final XGBoost model, trained on preprocessed data as described above, was compared with the XGBoost model trained on unprocessed data to assess the impact of the preprocessing techniques. Finally, we also assessed feature importance using Shapley values for machine learning models developed with and without preprocessing of the training data to assess the impact of the preprocessing procedure. We additionally compared feature importance for the final machine learning model across white and nonwhite racial groups.

Results

Patient demographic data from the MIMIC-III [22] database for the full cohort and after stratifying by race are presented in Table 1. A total of 28,460 patients were included in the final study sample, 23,263 (81.74%) of whom were white and 5197 (18.26%) of whom were nonwhite.

Several models were considered for predicting mortality. When compared with logistic regression and multilayer perceptron classification methods for their mortality prediction performance, the XGBoost model exhibited improved prediction performance as measured by AUROC, sensitivity, specificity, DOR, and LR+/- (Multimedia Appendix 1). Comparisons between XGBoost and other classification models were statistically significant ($P<.001$).

The final XGBoost model was trained to be unbiased by preprocessing the training data to ensure statistical equivalence of false negative rates for both white and nonwhite patient populations. The model outperformed all rules-based comparator scoring systems in predicting in-hospital mortality, achieving an AUROC of 0.78. The algorithm demonstrated improved sensitivity, specificity, DOR, and LR+/- as compared with comparator scores (Table 2). All pairwise comparisons between the algorithm and a rules-based comparator were statistically significant ($P<.001$, by McNemar test). Performance results for the machine learning algorithm on white and nonwhite patient populations are included in Multimedia Appendix 1.

Table 1. Demographic and medical information history for the Medical Information Mart for Intensive Care-III study sample by discharge status.

Characteristic	Full sample		White subset		Nonwhite subset	
	Living (n=19,269)	Deceased (n=9191)	Living (n=15,394)	Deceased (n=7896)	Living (n=3875)	Deceased (n=1322)
Female, n (%)	8129 (42.19)	4269 (46.45)	6313 (41.01)	3672 (46.66)	1816 (46.86)	597 (45.16)
Age, mean (SD)	60.11 (17.4)	71.31 (14.7)	61.4 (17.1)	71.91 (14.4)	54.99 (17.7)	67.73 (15.5)
Cardiovascular, n (%)	15,869 (82.36)	8085 (87.97)	12,790 (83.08)	6928 (88.04)	933 (24.08)	394 (29.80)
Renal, n (%)	5778 (29.99)	3867 (42.07)	4376 (28.43)	3243 (41.21)	391 (10.09)	201 (15.20)
Diabetes, types 1 and 2, n (%)	3843 (19.94)	1854 (20.17)	2903 (18.86)	1517 (19.28)	3079 (79.46)	1157 (87.52)
COPD ^a , n (%)	1626 (8.44)	1139 (12.39)	1428 (9.28)	1032 (13.11)	1402 (36.18)	624 (47.20)
Sepsis, n (%)	729 (3.78)	321 (3.49)	534 (3.47)	269 (3.42)	195 (5.03)	52 (3.93)
Severe sepsis, n (%)	3877 (20.12)	2517 (27.39)	2944 (19.12)	2123 (26.98)	712 (18.37)	322 (24.36)
Septic shock, n (%)	1823 (9.46)	1271 (13.83)	1432 (9.30)	1070 (13.60)	401 (10.35)	184 (13.92)
Mental health disorder, n (%)	7351 (38.15)	2994 (32.58)	5882 (38.21)	2563 (32.57)	1469 (37.91)	431 (32.60)
Pneumonia, n (%)	3265 (16.94)	2186 (23.78)	2553 (16.58)	1864 (23.69)	198 (5.11)	107 (8.09)
Liver ^b , n (%)	1602 (8.31)	1020 (11.10)	1201 (7.80)	836 (10.62)	940 (24.26)	337 (25.49)
Cancer, n (%)	2941 (15.26)	2766 (30.09)	2297 (14.92)	2335 (29.67)	644 (16.62)	431 (32.60)
HIV/AIDS, n (%)	201 (1.04)	102 (1.11)	115 (0.75)	62 (0.79)	86 (2.22)	40 (3.03)

^aCOPD: chronic obstructive pulmonary disease.

^bAcute and subacute necrosis of liver, chronic liver disease and cirrhosis, liver abscess and sequelae of chronic liver disease, and other disorders of liver.

The algorithm was found to be unbiased as measured by the equal opportunity difference score, with an insignificant P value for model bias and an equal opportunity difference of 0.016 ($P=.20$). The APACHE score was also found to be unbiased, with an equal opportunity difference of 0.019 ($P=.17$). However, both SAPS II and MEWS were found to have statistically significant bias as measured by equal opportunity difference, with equal opportunity difference values of 0.038 and 0.074 and P values of .006 and $<.001$, respectively.

Preprocessing of the training data was found to make a meaningful difference in model performance. On an XGBoost model trained on unprocessed data, the equal opportunity difference was found to be larger, at 0.023 ($P=.07$). A full comparison of models trained with and without data processing are presented in Multimedia Appendix 1. In assessing feature importance for models trained with and without preprocessing of the training data, we found differences in the importance of age and Glasgow coma scale features (Figure 2A), which may reflect differences in the distribution of age and life expectancy

across race in the general population and differences in disease severity upon presentation to the ICU across racial groups. In particular, nonwhite patients were generally found to be younger than white patients before preprocessing, indicating an

interaction between age and race on mortality outcome prediction. After preprocessing of the training data, feature importance was found to be similar for all measured features across racial groups (Figure 2B).

Table 2. Performance metrics for the machine learning algorithm and all comparator scores for mortality prediction on the total study population.

Statistics	MLA ^a	MEWS ^b	APACHE ^c	SAPS-II ^d
AUROC ^e	0.780	0.580	0.700	0.660
Sensitivity	0.751	0.523	0.678	0.674
Specificity	0.656	0.577	0.596	0.511
DOR ^f	5.739	1.499	3.106	2.157
LR+ ^g	2.181	1.238	1.678	1.378
LR- ^h	0.380	0.826	0.540	0.639

^aMLA: machine learning algorithm.

^bMEWS: Modified Early Warning Score.

^cAPACHE: Acute Physiologic Assessment and Chronic Health Evaluation.

^dSAPS II: Simplified Acute Physiology Score II.

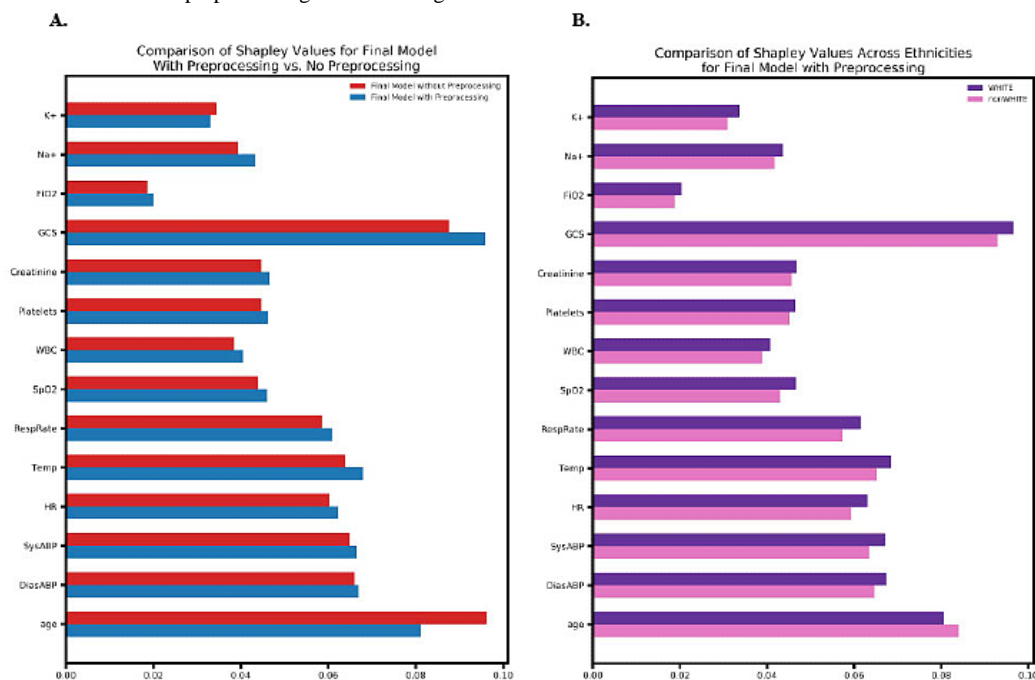
^eAUROC: area under the receiver operating characteristic.

^fDOR: diagnostic odds ratio.

^gLR+: positive likelihood ratio.

^hLR-: negative likelihood ratio.

Figure 2. Comparison of feature importance between (A) models trained with and without preprocessing of the training data and (B) white and nonwhite subgroups on the model trained with preprocessing of the training data.



Discussion

Principal Findings

In this study, we examined whether a machine learning algorithm is capable of predicting mortality with reduced racial bias as compared with commonly used early warning and severity scoring systems. We found evidence of statistically significant bias as measured by the equal opportunity difference

measures of MEWS and SAPS II, but no evidence of bias for the machine learning algorithm or for APACHE. In addition, the algorithm displayed better overall performance as measured by AUROC, sensitivity, specificity, DOR, and LR+/- . The combination of superior predictive performance and unbiased performance indicate that the machine learning algorithm may be more appropriate than any of the comparator scores for risk stratification in clinical settings as the algorithm appears most

capable of accurately identifying all patients at risk of in-hospital mortality.

The ability to demonstrate that a risk prediction tool can be used without inherent racial bias is a crucial step toward minimizing health care disparities. Large, well-designed cohort studies have found significant evidence of racial bias in commonly used scoring systems, including reduced accuracy of MEWS when implemented on an Asian population [23] and consistently lower acuity scores for nonwhite patients when examining the performance of the ESI [20-22]. This body of evidence indicates that nonwhite patients may be subject to inferior health care. Importantly, these persistent racial disparities in the provision of health care may be reflective of systematic failure to identify minority patients most likely to require immediate or aggressive care.

Continued research on ways to deliver equitable performance from systems such as MEWS and the ESI is essential. However, while machine learning algorithms can be subject to racial bias in their own right [7,9], well-designed algorithms may offer advantages over traditional scoring systems. These advantages are only present, however, if the algorithm is intentionally designed with the aim of minimizing racial bias. This paper has demonstrated the success of a preprocessing technique [7] that has benefits of making minimal alterations to the training data and not requiring costly alterations to the model training procedure. When machine learning prediction models are developed without this or a similar technique to counteract racial bias, algorithms used within the health system have been found to be less accurate for racial minorities. Obermeyer and colleagues [8] found that an algorithm commonly used across the United States had reduced accuracy for nonwhite patients due to the use of health care costs standing as a proxy for overall patient risk in the model output. Further, they found that minority patients generally had higher comorbidity index values when compared with white patients with the same overall risk score, indicating a systematic underestimation of the health care needs of nonwhite patients. Obermeyer and colleagues [8] found that reframing the model prediction task (in this case, from predicted costs to a measure of predicted health) minimized racial bias in model accuracy. A study by Chen et al [9] similarly found that machine learning algorithms displayed higher error rates when predicting psychiatric readmission and mortality in minority patients as compared with white patients.

This research seeks to fill a gap beyond addressing bias that can occur with clinical diagnostic testing. In addition, it adds to the body of evidence regarding how systemic health care inequalities emerge and persist and shows that poor calibration of traditional prediction scores as pertains to nonwhite populations can potentially influence health care decision

making in the United States [29,30]. Although more research is needed to assess bias and disparities across a wide range of settings and applications, the potential harm that can come from bias in simple severity scores is made clear by recent recommendations surrounding COVID-19. Several recommendations for providing care and allocating limited resources have suggested that aggressive treatment be provided to patients based on assessment by MEWS, SAPS II, APACHE, or similar severity scores [31-33]. However, bias in severity scores used to triage COVID-19 patients could widen existing racial disparities in COVID-19 [34], and this work makes clear that less biased methods are achievable and preferable for such uses.

Limitations

This study has several important limitations. First, the study used retrospective patient medical records. There are known inaccuracies in the way that race and ethnicity are recorded in medical records; this in turn may have impacted the accuracy of our results [35]. Additionally, our analysis compared nonwhite to white patients and did not consider more nuanced categories of racial identity. There may be nuances in the accuracy of the algorithm and its comparators across these groups. We also note that overall, our study sample was largely white, with only around 18% of our sample reporting nonwhite race or ethnicity. The predominance of white patients in this study may have biased results; validation of this model on additional datasets is warranted. Research has indicated the potential for bias in the way that seemingly objective measures such as heart rate, respiratory rate, and spirometry, as well as pain assessments, are made across racial groups [22,36-38]. Lab measurements also pose the potential for bias due to the incorporation of race corrections in measures such as estimated glomerular filtration rate. Additionally, there are further ways of measuring and assessing discriminatory predictive performance not assessed in this paper. This is a retrospective study, and we therefore cannot determine the impact this algorithm will have on patient care in a live health care setting.

Conclusions

We believe that the potential for bias through this mechanism is mitigated in our machine learning method as compared with rules-based methods. This is due to our incorporation of several laboratory measures collected using standardized methods not incorporating race corrections, use of measurements obtained at a variety of time points and therefore likely assessed by a variety of clinicians, and statistical methods used to minimize bias during the model training process. Despite its limitations, the algorithm examined in this study shows promise as one of many necessary steps toward decreasing racial disparities in health care.

Acknowledgments

We gratefully acknowledge Megan Handley for her work in editing this manuscript.

Authors' Contributions

AA contributed to the data analysis and writing of this study. SM contributed to the conception and revision of this study. AS, EP, JH, AGS, HB, GB, RPD, AM, and GB contributed to the writing and revision of this study. JC contributed to the conception of this study. RD contributed to the conception and revision of this study.

Conflicts of Interest

AA, SM, AS, EP, JH, AGS, GB, JC, and RD are employees or contractors of Dascena. The other authors declare no conflict of interest.

Multimedia Appendix 1

Supplementary materials.

[\[DOCX File, 21 KB - publichealth_v6i4e22400_app1.docx\]](#)

References

1. Weinstein JN. In: Weinstein JN, Geller A, Negussie Y, Baciu A, editors. *Communities in Action: Pathways to Health Equity*. Washington: National Academies Press; 2017.
2. Wheeler SM, Bryant AS. Racial and ethnic disparities in health and health care. *Obstet Gynecol Clin North Am* 2017 Mar;44(1):1-11. [doi: [10.1016/j.ogc.2016.10.001](https://doi.org/10.1016/j.ogc.2016.10.001)] [Medline: [28160887](https://pubmed.ncbi.nlm.nih.gov/28160887/)]
3. Siddiqi AA, Wang S, Quinn K, Nguyen QC, Christy AD. Racial disparities in access to care under conditions of universal coverage. *Am J Prev Med* 2016 Feb;50(2):220-225. [doi: [10.1016/j.amepre.2014.08.004](https://doi.org/10.1016/j.amepre.2014.08.004)] [Medline: [25441235](https://pubmed.ncbi.nlm.nih.gov/25441235/)]
4. Fiscella K, Sanders MR. Racial and ethnic disparities in the quality of health care. *Annu Rev Public Health* 2016;37:375-394. [doi: [10.1146/annurev-publhealth-032315-021439](https://doi.org/10.1146/annurev-publhealth-032315-021439)] [Medline: [26789384](https://pubmed.ncbi.nlm.nih.gov/26789384/)]
5. Musa D, Schulz R, Harris R, Silverman M, Thomas SB. Trust in the health care system and the use of preventive health services by older black and white adults. *Am J Public Health* 2009 Jul;99(7):1293-1299. [doi: [10.2105/AJPH.2007.123927](https://doi.org/10.2105/AJPH.2007.123927)] [Medline: [18923129](https://pubmed.ncbi.nlm.nih.gov/18923129/)]
6. Feagin J, Bennefield Z. Systemic racism and U.S. health care. *Soc Sci Med* 2014 Feb;103:7-14. [doi: [10.1016/j.socscimed.2013.09.006](https://doi.org/10.1016/j.socscimed.2013.09.006)] [Medline: [24507906](https://pubmed.ncbi.nlm.nih.gov/24507906/)]
7. Kamiran F, Calders T. Data preprocessing techniques for classification without discrimination. *Knowl Inf Syst* 2011 Dec 3;33(1):1-33. [doi: [10.1007/s10115-011-0463-8](https://doi.org/10.1007/s10115-011-0463-8)]
8. Obermeyer Z, Powers B, Vogeli C, Mullainathan S. Dissecting racial bias in an algorithm used to manage the health of populations. *Science* 2019 Oct 25;366(6464):447-453. [doi: [10.1126/science.aax2342](https://doi.org/10.1126/science.aax2342)] [Medline: [31649194](https://pubmed.ncbi.nlm.nih.gov/31649194/)]
9. Chen IY, Szolovits P, Ghassemi M. Can AI help reduce disparities in general medical and mental health care? *AMA J Ethics* 2019 Feb 01;21(2):E167-E179 [FREE Full text] [doi: [10.1001/amajethics.2019.167](https://doi.org/10.1001/amajethics.2019.167)] [Medline: [30794127](https://pubmed.ncbi.nlm.nih.gov/30794127/)]
10. Vyas DA, Eisenstein LG, Jones DS. Hidden in plain sight—reconsidering the use of race correction in clinical algorithms. *N Engl J Med* 2020 Aug 27;383(9):874-882. [doi: [10.1056/NEJMms2004740](https://doi.org/10.1056/NEJMms2004740)] [Medline: [32853499](https://pubmed.ncbi.nlm.nih.gov/32853499/)]
11. Peterson PN, Rumsfeld JS, Liang L, Albert NM, Hernandez AF, Peterson ED, American Heart Association Get With the Guidelines-Heart Failure Program. A validated risk score for in-hospital mortality in patients with heart failure from the American Heart Association Get with the Guidelines program. *Circ Cardiovasc Qual Outcomes* 2010 Jan;3(1):25-32. [doi: [10.1161/CIRCOUTCOMES.109.854877](https://doi.org/10.1161/CIRCOUTCOMES.109.854877)] [Medline: [20123668](https://pubmed.ncbi.nlm.nih.gov/20123668/)]
12. Levey AS, Stevens LA, Schmid CH, Zhang YL, Castro AF, Feldman HI, et al. A new equation to estimate glomerular filtration rate. *Ann Intern Med* 2009 May 05;150(9):604-612 [FREE Full text] [Medline: [19414839](https://pubmed.ncbi.nlm.nih.gov/19414839/)]
13. Grobman WA, Lai Y, Landon MB, Spong CY, Leveno KJ, Rouse DJ, National Institute of Child Health and Human Development (NICHD) Maternal-Fetal Medicine Units Network (MFMU). Development of a nomogram for prediction of vaginal birth after cesarean delivery. *Obstet Gynecol* 2007 Apr;109(4):806-812. [doi: [10.1097/01.AOG.0000259312.36053.02](https://doi.org/10.1097/01.AOG.0000259312.36053.02)] [Medline: [17400840](https://pubmed.ncbi.nlm.nih.gov/17400840/)]
14. Shahian DM, Jacobs JP, Badhwar V, Kurlansky PA, Furnary AP, Cleveland JC, et al. The Society of Thoracic Surgeons 2018 adult cardiac surgery risk models: Part 1—background, design considerations, and model development. *Ann Thorac Surg* 2018 May;105(5):1411-1418. [doi: [10.1016/j.athoracsur.2018.03.002](https://doi.org/10.1016/j.athoracsur.2018.03.002)] [Medline: [29577925](https://pubmed.ncbi.nlm.nih.gov/29577925/)]
15. Subbe CP, Slater A, Menon D, Gemmell L. Validation of physiological scoring systems in the accident and emergency department. *Emerg Med J* 2006 Nov;23(11):841-845 [FREE Full text] [doi: [10.1136/emj.2006.035816](https://doi.org/10.1136/emj.2006.035816)] [Medline: [17057134](https://pubmed.ncbi.nlm.nih.gov/17057134/)]
16. Salottolo K, Carrick M, Johnson J, Gamber M, Bar-Or D. A retrospective cohort study of the utility of the modified early warning score for interfacility transfer of patients with traumatic injury. *BMJ Open* 2017 May 09;7(5):e016143. [doi: [10.1136/bmjopen-2017-016143](https://doi.org/10.1136/bmjopen-2017-016143)] [Medline: [28490566](https://pubmed.ncbi.nlm.nih.gov/28490566/)]
17. Fullerton JN, Price CL, Silvey NE, Brace SJ, Perkins GD. Is the Modified Early Warning Score (MEWS) superior to clinician judgement in detecting critical illness in the pre-hospital environment? *Resuscitation* 2012 May;83(5):557-562. [doi: [10.1016/j.resuscitation.2012.01.004](https://doi.org/10.1016/j.resuscitation.2012.01.004)] [Medline: [22248688](https://pubmed.ncbi.nlm.nih.gov/22248688/)]

18. Patel R, Nugawela MD, Edwards HB, Richards A, Le Roux H, Pullyblank A, et al. Can early warning scores identify deteriorating patients in pre-hospital settings? A systematic review. *Resuscitation* 2018 Nov;132:101-111 [FREE Full text] [doi: [10.1016/j.resuscitation.2018.08.028](https://doi.org/10.1016/j.resuscitation.2018.08.028)] [Medline: [30171976](https://pubmed.ncbi.nlm.nih.gov/30171976/)]
19. Emergency Severity Index (ESI): a triage tool for emergency departments. Rockville: Agency for Healthcare Research and Quality URL: <https://www.ahrq.gov/professionals/systems/hospital/esi/index.html> [accessed 2020-10-07]
20. Schrader CD, Lewis LM. Racial disparity in emergency department triage. *J Emerg Med* 2013 Feb;44(2):511-518. [doi: [10.1016/j.jemermed.2012.05.010](https://doi.org/10.1016/j.jemermed.2012.05.010)] [Medline: [22818646](https://pubmed.ncbi.nlm.nih.gov/22818646/)]
21. Zook HG, Kharbanda AB, Flood A, Harmon B, Puumala SE, Payne NR. Racial differences in pediatric emergency department triage scores. *J Emerg Med* 2016 May;50(5):720-727 [FREE Full text] [doi: [10.1016/j.jemermed.2015.02.056](https://doi.org/10.1016/j.jemermed.2015.02.056)] [Medline: [26899520](https://pubmed.ncbi.nlm.nih.gov/26899520/)]
22. Vigil JM, Coulombe P, Alcock J, Kruger E, Stith SS, Strenth C, et al. Patient ethnicity affects triage assessments and patient prioritization in U.S. Department of Veterans Affairs Emergency Departments. *Medicine (Baltimore)* 2016 Apr;95(14):e3191 [FREE Full text] [doi: [10.1097/MD.00000000000003191](https://doi.org/10.1097/MD.00000000000003191)] [Medline: [27057847](https://pubmed.ncbi.nlm.nih.gov/27057847/)]
23. Ho LO, Li H, Shahidah N, Koh ZX, Sultana P, Hock Ong ME. Poor performance of the modified early warning score for predicting mortality in critically ill patients presenting to an emergency department. *World J Emerg Med* 2013;4(4):273-278 [FREE Full text] [doi: [10.5847/wjem.j.issn.1920-8642.2013.04.005](https://doi.org/10.5847/wjem.j.issn.1920-8642.2013.04.005)] [Medline: [25215131](https://pubmed.ncbi.nlm.nih.gov/25215131/)]
24. Mohamadlou H, Panchavati S, Calvert J, Lynn-Palevsky A, Le S, Allen A, et al. Multicenter validation of a machine-learning algorithm for 48-h all-cause mortality prediction. *Health Informatics J* 2020 Sep;26(3):1912-1925. [doi: [10.1177/1460458219894494](https://doi.org/10.1177/1460458219894494)] [Medline: [31884847](https://pubmed.ncbi.nlm.nih.gov/31884847/)]
25. Le Gall JR, Lemeshow S, Saulnier F. A new Simplified Acute Physiology Score (SAPS II) based on a European/North American multicenter study. *JAMA* 1993;270(24):2957-2963. [Medline: [8254858](https://pubmed.ncbi.nlm.nih.gov/8254858/)]
26. Knaus WA, Draper EA, Wagner DP, Zimmerman JE. APACHE II: a severity of disease classification system. *Crit Care Med* 1985 Oct;13(10):818-829. [Medline: [3928249](https://pubmed.ncbi.nlm.nih.gov/3928249/)]
27. Johnson AEW, Pollard TJ, Shen L, Lehman LH, Feng M, Ghassemi M, et al. MIMIC-III, a freely accessible critical care database. *Sci Data* 2016;3:160035 [FREE Full text] [doi: [10.1038/sdata.2016.35](https://doi.org/10.1038/sdata.2016.35)] [Medline: [27219127](https://pubmed.ncbi.nlm.nih.gov/27219127/)]
28. Chen T, Guestrin C. XGBoost: A Scalable Tree Boosting System. San Francisco California USA; 2016 Presented at: Proceedings of the 22nd ACM SIGKDD International Conference on Knowledge Discovery and Data Mining; 2016; San Francisco. [doi: [10.1145/2939672.2939785](https://doi.org/10.1145/2939672.2939785)]
29. Weinstein JN. The state of health disparities in the United States. In: Weinstein JN, Baciu A, Negussie Y, Geller A, editors. *Communities in Action: Pathways to Health Equity*. Washington: National Academies Press; 2017:57-98.
30. Hall WJ, Chapman MV, Lee KM, Merino YM, Thomas TW, Payne BK, et al. Implicit racial/ethnic bias among health care professionals and its influence on health care outcomes: a systematic review. *Am J Public Health* 2015 Dec;105(12):e60-e76. [doi: [10.2105/AJPH.2015.302903](https://doi.org/10.2105/AJPH.2015.302903)] [Medline: [26469668](https://pubmed.ncbi.nlm.nih.gov/26469668/)]
31. Feinstein MM, Niforatos JD, Hyun I, Cunningham TV, Reynolds A, Brodie D, et al. Considerations for ventilator triage during the COVID-19 pandemic. *Lancet Respir Med* 2020 Jun;8(6):e53 [FREE Full text] [doi: [10.1016/S2213-2600\(20\)30192-2](https://doi.org/10.1016/S2213-2600(20)30192-2)] [Medline: [32444270](https://pubmed.ncbi.nlm.nih.gov/32444270/)]
32. Maves RC, Downar J, Dichter JR, Hick JL, Devereaux A, Geiling JA, ACCP Task Force for Mass Critical Care. Triage of scarce critical care resources in COVID-19: an implementation guide for regional allocation: an expert panel report of the Task Force for Mass Critical Care and the American College of Chest Physicians. *Chest* 2020 Jul;158(1):212-225 [FREE Full text] [doi: [10.1016/j.chest.2020.03.063](https://doi.org/10.1016/j.chest.2020.03.063)] [Medline: [32289312](https://pubmed.ncbi.nlm.nih.gov/32289312/)]
33. Solomon MZ, Wynia MK, Gostin LO. Covid-19 crisis triage—optimizing health outcomes and disability rights. *N Engl J Med* 2020 Jul 30;383(5):e27. [doi: [10.1056/NEJMp2008300](https://doi.org/10.1056/NEJMp2008300)] [Medline: [32427434](https://pubmed.ncbi.nlm.nih.gov/32427434/)]
34. Webb Hooper M, Nápoles AM, Pérez-Stable EJ. COVID-19 and racial/ethnic disparities. *JAMA* 2020 Jun 23;323(24):2466-2467. [doi: [10.1001/jama.2020.8598](https://doi.org/10.1001/jama.2020.8598)] [Medline: [32391864](https://pubmed.ncbi.nlm.nih.gov/32391864/)]
35. Polubriaginof FCG, Ryan P, Salmasian H, Shapiro AW, Perotte A, Safford MM, et al. Challenges with quality of race and ethnicity data in observational databases. *J Am Med Inform Assoc* 2019 Aug 01;26(8-9):730-736 [FREE Full text] [doi: [10.1093/jamia/ocz113](https://doi.org/10.1093/jamia/ocz113)] [Medline: [31365089](https://pubmed.ncbi.nlm.nih.gov/31365089/)]
36. Cao Y, Contreras-Huerta LS, McFadyen J, Cunningham R. Racial bias in neural response to others' pain is reduced with other-race contact. *Cortex* 2015 Sep;70:68-78 [FREE Full text] [doi: [10.1016/j.cortex.2015.02.010](https://doi.org/10.1016/j.cortex.2015.02.010)] [Medline: [25798570](https://pubmed.ncbi.nlm.nih.gov/25798570/)]
37. Hoffman KM, Trawalter S, Axt JR, Oliver MN. Racial bias in pain assessment and treatment recommendations, and false beliefs about biological differences between blacks and whites. *Proc Natl Acad Sci USA* 2016 Apr 19;113(16):4296-4301. [doi: [10.1073/pnas.1516047113](https://doi.org/10.1073/pnas.1516047113)] [Medline: [27044069](https://pubmed.ncbi.nlm.nih.gov/27044069/)]
38. Braun L. Race, ethnicity and lung function: a brief history. *Can J Respir Ther* 2015;51(4):99-101 [FREE Full text] [Medline: [26566381](https://pubmed.ncbi.nlm.nih.gov/26566381/)]

Abbreviations

AI: artificial intelligence

APACHE: Acute Physiologic Assessment and Chronic Health Evaluation

AUROC: area under the receiver operating characteristic
DOR: diagnostic odds ratio
ESI: emergency severity index
ICU: intensive care unit
LR+: positive likelihood ratio
LR-: negative likelihood ratio
MEWS: Modified Early Warning Score
MIMIC-III: Medical Information Mart for Intensive Care-III
SAPS II: Simplified Acute Physiology Score II

Edited by M Focsa; submitted 10.07.20; peer-reviewed by K Ferryman, C Davis; comments to author 22.09.20; revised version received 25.09.20; accepted 01.10.20; published 22.10.20.

Please cite as:

Allen A, Mataraso S, Siefkas A, Burdick H, Braden G, Dellinger RP, McCoy A, Pellegrini E, Hoffman J, Green-Saxena A, Barnes G, Calvert J, Das R

A Racially Unbiased, Machine Learning Approach to Prediction of Mortality: Algorithm Development Study

JMIR Public Health Surveill 2020;6(4):e22400

URL: <http://publichealth.jmir.org/2020/4/e22400/>

doi: [10.2196/22400](https://doi.org/10.2196/22400)

PMID: [33090117](https://pubmed.ncbi.nlm.nih.gov/33090117/)

©Angier Allen, Samson Mataraso, Anna Siefkas, Hoyt Burdick, Gregory Braden, R Phillip Dellinger, Andrea McCoy, Emily Pellegrini, Jana Hoffman, Abigail Green-Saxena, Gina Barnes, Jacob Calvert, Ritankar Das. Originally published in JMIR Public Health and Surveillance (<http://publichealth.jmir.org>), 22.10.2020. This is an open-access article distributed under the terms of the Creative Commons Attribution License (<https://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in JMIR Public Health and Surveillance, is properly cited. The complete bibliographic information, a link to the original publication on <http://publichealth.jmir.org>, as well as this copyright and license information must be included.

Original Paper

Perspective of an International Online Patient and Caregiver Community on the Burden of Spasticity and Impact of Botulinum Neurotoxin Therapy: Survey Study

Atul T Patel^{1*}, MD; Theodore Wein^{2*}, MD; Laxman B Bahroo^{3*}, MD; Ophélie Wilczynski^{4*}, MSc; Carl D Rios^{5*}, PhD; Manuel Murie-Fernández^{6*}, MD

¹Kansas City Bone & Joint Clinic, Overland Park, KS, United States

²Department of Neurology and Neurosurgery, McGill University, Montreal, QC, Canada

³Department of Neurology, Georgetown University, Georgetown, DC, United States

⁴Carenity, Paris, France

⁵Ipsen Pharma, Boulogne-Billancourt, France

⁶Neurorehabilitation Unit, Ciudad de Telde Hospital, Las Palmas, Spain

* all authors contributed equally

Corresponding Author:

Atul T Patel, MD

Kansas City Bone & Joint Clinic

10701 Nall Ave #200

Overland Park, KS, 66211

United States

Phone: 1 913 381 5225

Email: apatel@KCBJ.com

Abstract

Background: Patient- and caregiver-reported data are lacking on the burden of spasticity, and the impact of botulinum neurotoxin type A (BoNT-A) treatment for this condition, on patients' daily lives. As recommended in recent guidance from the US Food and Drug Administration, online patient communities can represent a platform from which to gather specific information outside of a clinical trial setting on the burden of conditions experienced by patients and caregivers and their views on treatment options in order to inform evidence-based medicine and drug development.

Objective: The objective of our study is to characterize spasticity symptoms and their associated burdens on Western European and US patients and caregivers in the realms of work, daily activities, quality of life (QoL), as well as the positive and negative impacts of treatment with BoNT-A (cost, time, QoL) using Carenity, an international online community for people with chronic health conditions.

Methods: We performed a noninterventional, multinational survey. Eligible participants were 18 years old or older and had, or had cared for, someone with spasticity who had been treated with BoNT-A for at least 1 year. Patients and caregivers were asked to complete an internet-based survey via Carenity; caregivers reported their own answers and answered on behalf of their patients. Questions included the burden of spasticity on the ability to work, functioning, daily-living activities, and QoL, the impact of BoNT A therapy on patients' lives, and the potential benefits of fewer injections.

Results: There were 615 respondents (427 patients and 188 caregivers). The mean age of patients and caregivers was 41.7 years and 38.6 years, respectively, and the most commonly reported cause of spasticity was multiple sclerosis. Caregivers were most often the parents (76/188, 40%) or another family member (51/188, 27%) of their patients. Spasticity had a clear impact on patients' and caregivers' lives, including the ability to work and injection costs. For patients, spasticity caused difficulties with activities of daily living and reduced QoL indices. The median number of BoNT-A injections was 4 times per year, and 92% (393/427) of patients reported that treatment improved their overall satisfaction with life. Regarding the BoNT-A injection burden, the greatest patient-reported challenges were the cost and availability of timely appointments. Overall, 86% (368/427) of patients believed that a reduced injection frequency would be beneficial. Caregivers answering for their patients gave largely similar responses to those reported by patients.

Conclusions: Spasticity has a negative impact on both patients' and caregivers' lives. All respondents reported that BoNT A treatment improved their lives, despite the associated challenges. Patients believed that reducing the frequency of BoNT-A injections could alleviate practical issues associated with treatment, implying that a longer-acting BoNT-A injection would be well received.

(*JMIR Public Health Surveill* 2020;6(4):e17928) doi:[10.2196/17928](https://doi.org/10.2196/17928)

KEYWORDS

spasticity; activities of daily living; quality of life; survey methodology

Introduction

Knowledge of patient and caregiver perspectives on a disease and related therapies help identify relevant patient-reported outcomes for assessment in clinical trials and inform clinical decision-making; therefore, it is critical for patient-focused drug development. Methodological guidance to support the collection of patient experience data has recently been published by the US Food and Drug Administration (FDA), which includes the utilization of online patient communities [1]. An increasing number of internet-based platforms are available to patients for their participation in scientific research, ranging from registry data, forums, social networks, and online communities. Online patient communities offer the opportunity to voluntarily express experiences and feelings outside of the clinical setting regarding the treatments for their condition and the burden on their quality of life (QoL) [2]. These data, along with any epidemiological information, can provide researchers with a better understanding of the patient journey for a given disease and are important in clinical judgment and decision making for evidence-based medicine [2]. The internet provides a vast potential resource for real-world data collection during scientific studies, which, along with exploring patient expectations and unmet needs, may help develop or support study protocols and methodologies and enhance recruitment for research. Developed in 2011, Carenity is an international online patient community for people with chronic conditions [3]. Currently, 500,000 members are registered on the platform, which allows both patients and their families to share their experiences, follow the evolution of their health, and contribute to medical research through online surveys.

Spasticity is caused by an upper motor neuron lesion leading to intermittent or sustained involuntary activation of muscles [4] and is a sequela from a range of central nervous system (CNS) disorders affecting over 12 million people worldwide [5]. The prevalence of spasticity differs between etiologies, which include stroke (40%), multiple sclerosis (MS, 80%), spinal cord (65%) or traumatic brain (17-50%) injury, and cerebral palsy (90%) [6-11]. Left untreated, spasticity becomes burdensome both physically and economically for patients and their caregivers. Pain, spasms, limb contracture, and deformity can be experienced by patients with spasticity, leading to impairment of dexterity, mobility, and self-care, and ultimately, to decreased functioning and participation [12,13]. In an international survey of 281 patients with spasticity, 72% reported a negative impact on QoL and 44% reported a loss of independence [14]. Most respondents (64%) were cared for by family members, approximately 50% of whom had to reduce

work hours or stop working in order to be a caregiver [14]. Spasticity also places an economic burden on patients, caregivers, and health care systems [14-16].

Treatment of spasticity is indicated when it interferes with function or QoL. As spasticity can change over time, patients should undergo continuous re-evaluation [13]. Treatment options for spasticity include physical and pharmacological therapies, as well as surgery in severe or intractable cases [13]. In addition to relieving symptoms, treatment aims to improve patients' functioning. Specifically, spasticity management should focus on achieving the patient's goals and the goals of caregivers and health care providers [13]. These may include goals associated with moving and walking, self-care, pain, changing and maintaining body positions, improving positions to participate in rehabilitation, and enabling orthotic use [17].

Botulinum neurotoxin type A (BoNT-A) is integral to focal and multifocal spasticity management [13] and has proven antispastic efficacy in stroke [18], CNS lesions [19,20], MS [21], and cerebral palsy [22,23]. Although recent studies have demonstrated improvements in active function following repeated injection cycles with abobotulinumtoxinA (aboBoNT-A) in adult patients with upper and lower limb spasticity [24,25], more evidence is needed to document functional improvements following BoNT-A treatment [18,26,27]. Historically, clinical studies have not recorded patient and caregiver perspectives on disease burden; thus, limited information is currently available on the impact of attending appointments, receiving BoNT-A injections, and the therapeutic outcomes of BoNT-A treatment on the daily lives of patients and their caregivers. In the only study published to date on this topic, caregiver burden has been shown to lessen with BoNT-A treatment for spasticity [28]. In another study in patients with dystonia who received BoNT treatment, the related caregiver burden appeared to be low but greater in those caring for patients who had more severe symptoms that had a greater impact on health-related QoL [29].

The aim of this study is to characterize spasticity symptoms and understand their burden, as well as the impact of BoNT-A injections, from the patient and caregiver perspective. The ability to work, perform daily activities, and QoL were assessed, as well as the perceived benefits and challenges associated with BoNT-A treatment with a focus on injection frequency.

Methods

Survey Design

The survey was conducted in France, Germany, Italy, Spain, the United Kingdom, and the United States between November

10, 2017, and February 28, 2018, using an established online approach [30-32]. Patients or caregivers of patients with spasticity who were members of the Carenity platform were invited by email to complete a questionnaire, presented in the local language, translated by a specialized agency and reviewed by local Carenity community managers. The study methodology and questionnaire were validated by 3 neurologists (from Canada, Spain, and the United States) and 1 rehabilitation physician (from the United States). To ensure language suitability, a patient who matched the study inclusion criteria was selected via the Carenity platform and asked to proofread the questionnaire.

All questions were the same between countries except for those relating to BoNT-A formulation brand names, which were removed from the Spanish questionnaire to comply with Spanish regulations. The study had a prespecified target of 600 respondents: included 300 from the United States and 300 from Europe, determined using the Cochran formula, with p set at 0.5 (maximum variability), the confidence level at 95%, and a maximum margin of error between 5% and 6% for each region.

Survey Questionnaire

The questionnaire comprised multiple-choice, sliding-scale, or free-text answers and consisted of 4 sections ([Multimedia Appendix 1](#)). For caregivers, some questions related to the patient they cared for, whereas others related specifically to their caregiver experiences. The first section of questions collected information on the patient's/caregiver's profiles (sex, age, spasticity diagnosis and symptoms, treatments for spasticity, duration of BoNT-A treatment, BoNT-A formulation, relationship to patient, duration and frequency of caregiving). Respondents were screened out of the survey at this stage if the eligibility criteria were not met. In countries other than Spain, patients selected the BoNT-A formulation from the following list: Dysport (aboBoNT-A), Xeomin (incobotulinumtoxinA, incoBoNT-A), Botox (onabotulinumtoxinA; onaBoNT-A), or "not known." Patients in Spain were asked to state the BoNT-A treatment they were receiving (if known) in a free-text field.

The second section collected information on the impact of spasticity on the ability to work, functioning, and QoL. The third section collected information on BoNT-A treatment behavior (goals, number of injections, and retreatment) and the impact of BoNT-A injections on patients' and caregivers' QoL. The final section collected information on the potential impact of reduced BoNT-A injection frequency on patients and caregivers (assuming efficacy was maintained). The sliding-scale questions in these sections are shown in [Multimedia Appendix 1](#).

The responses provided by the patients or caregivers regarding the patients' condition were self-reported and were not verified by an independent rater or reviewer. Free-text responses were categorized both automatically and manually (as appropriate)

by Carenity personnel, who also developed a tool to program and code the questionnaire.

Eligibility Criteria

Eligible participants were adult patients (≥ 18 years old) who self-reported as having spasticity and receiving treatment with BoNT-A for ≥ 1 year, and caregivers of patients meeting the survey criteria (caregivers were not those of the participating patients). Spasticity had to be due to MS, stroke, traumatic brain injury, spinal cord injury, cerebral palsy, brain tumor, or spastic paraplegia. Patients treated with oral antispasticity medications (eg, baclofen) or receiving concurrent physiotherapy (at home or in hospital) were permitted to participate.

Statistical Analyses

Descriptive analyses are presented: categorical variables are presented as frequency counts and percentages. Differences in reported burden, treatment behavior, and perceived benefits of fewer injections are compared between patients by limbs affected, level of difficulty experienced due to spasticity, symptoms experienced, and treatment received (number of injections).

Compliance

The study was conducted in accordance with Good Pharmacovigilance Practices Modules IV and VIII in compliance with relevant codes of conduct and data protection legislation, with no approval from the Clinical Research Ethics Committee or Independent Review Board required. All participants provided informed consent to participate and were made aware that the research was sponsored by a pharmaceutical company that manufactures a product approved for the treatment of spasticity.

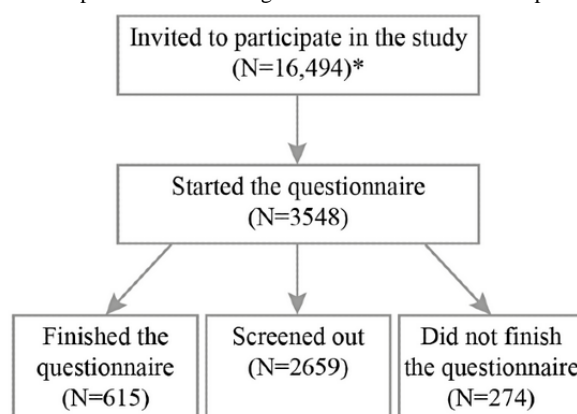
Funding and Data Sharing

This study was sponsored by Ipsen. Where patient data can be anonymized, Ipsen will share all data that underlie the results reported in this paper with qualified researchers who provide a valid research question. Study documents, such as the study protocol and clinical study report, are not always available. Proposals should be submitted to DataSharing@Ipsen.com and will be assessed by a scientific review board. Data are available beginning 6 months and ending 5 years after publication; after this time, only raw data may be available.

Results

Patient Demographics and Clinical Characteristics

Carenity invited 16,494 members (who had agreed to receive invitations to participate in questionnaires) from their community of members affected by spasticity or one of the targeted diseases to complete the survey and, of these, 3548 members started the survey ([Figure 1](#)). Participants were screened out of the study if they did not meet the eligibility criteria ($n=2,659$), and 274 participants did not complete the questionnaire.

Figure 1. Disposition of survey respondents. *Respondents who had agreed to receive invitations to participate in questionnaires.

In total, 615 participants completed the survey (427 patients and 188 caregivers), and the survey was closed (United States, 300/615, 49%; Europe, 315/615, 51%; [Table 1](#)). Patients had a mean age of 41.7 (95% CI 40.6-42.8) years; 48% (206/427) were women, 51% (216/427) were men, and 1% (5/427) were transgender.

The mean age at diagnosis was 33.5 (95% CI 32.3-34.7) years, and the mean time since diagnosis was 8.3 (95% CI 7.4-9.3) years. More patients had spasticity due to MS (199/427, 47%) than other conditions ([Table 1](#)). The proportion of patients with MS was lower in the United States (65/178, 37%) than in Europe (134/249, 54%; [Multimedia Appendix 2](#)). The most frequent symptoms of spasticity were muscle spasms, stiffness/rigidity, and muscle pain ([Table 1](#)).

The current BoNT-A treatment was onabotulinum toxin A (onaBoNT-A) for most patients (237/427, 56%), with 18% (75/427) receiving abobotulinum toxin A (aboBoNT-A) and 11% (48/427) receiving incobotulinum toxin A (incoBoNT-A) ([Table 1](#)). The mean time since the first BoNT-A treatment was 3.5 (95% CI 3.0-3.9) years, suggesting an average gap of 4.8 years between diagnosis and BoNT-A initiation. More patients from the participating European countries did not know which formulation they were taking (21% vs 6% for the United States; [Multimedia Appendix 2](#)). In total, 60% (256/427) of patients were receiving concurrent oral medication (eg, muscle relaxants or baclofen), 69% (297/427) were receiving physiotherapy (35% at home, 34% in hospital), 11% (45/427) had received phenol, 9% (40/427) had received botulinum neurotoxin type B injections, and 7% (29/427) had received alcohol ([Table 1](#)).

Table 1. Participant characteristics (N=615).

Characteristic	Patients (n=427)	Caregivers (n=188)	Caregivers' patients (n=188)
Age in years, n (%)			
18-30	72 (17)	49 (26)	24 (13)
31-40	127 (30)	63 (34)	15 (8)
41-50	134 (31)	45 (24)	25 (13)
51-65	79 (19)	27 (14)	53 (28)
≥66	15 (4)	4 (2)	71 (38)
Gender, n (%)			
Men	216 (51)	84 (45)	84 (45)
Women	206 (48)	104 (55)	104 (55)
Transgender	5 (1)	0 (0)	0 (0)
Relationship of patient to caregiver, n (%)			
Parent	N/A ^a	76 (40)	N/A
Another family member	N/A	51 (27)	N/A
Friend	N/A	17 (9)	N/A
Partner	N/A	14 (7)	N/A
Child	N/A	11 (6)	N/A
Sibling	N/A	11 (6)	N/A
Neighbor	N/A	6 (3)	N/A
Other	N/A	2 (1)	N/A
Frequency (days per week) of caregiving, n (%)			
≥1	N/A	14 (7)	N/A
≥2	N/A	27 (14)	N/A
≥4	N/A	62 (33)	N/A
Daily	N/A	85 (45)	N/A
Duration of caregiving in years, n (%)			
<1	N/A	11 (6)	N/A
1-3	N/A	64 (34)	N/A
3-5	N/A	46 (24)	N/A
5-10	N/A	45 (24)	N/A
>10	N/A	22 (12)	N/A
Cause of spasticity, n (%)			
Brain tumor	13 (3)	N/A	5 (3)
Cerebral palsy	31 (7)	N/A	19 (10)
Multiple sclerosis	199 (47)	N/A	57 (30)
Spastic paraplegia	41 (10)	N/A	20 (11)
Spinal cord injury	40 (9)	N/A	20 (11)
Stroke	69 (16)	N/A	53 (28)
Traumatic brain injury	34 (8)	N/A	14 (7)
Time (in years) since diagnosis, n (%)			
<3	140 (33)	N/A	44 (23)
3-5	61 (14)	N/A	42 (22)
5-10	79 (19)	N/A	57 (30)

Characteristic	Patients (n=427)	Caregivers (n=188)	Caregivers' patients (n=188)
10-15	54 (13)	N/A	10 (5)
>15	74 (17)	N/A	30 (16)
Not specified	19 (4)	N/A	5 (3)
Symptoms experienced, n (%)			
Difficulties using arm(s)	194 (45)	N/A	108 (57)
Difficulties using legs	286 (67)	N/A	133 (71)
Muscle pain	295 (69)	N/A	129 (69)
Muscle spasms	308 (72)	N/A	125 (66)
Muscle stiffness/rigidity	295 (69)	N/A	136 (72)
Unwanted movement of the stiff limb	176 (41)	N/A	64 (34)
Botulinum neurotoxin type A treatment received,^b n (%)			
AbobotulinumtoxinA	75 (18)	N/A	34 (18)
IncobotulinumtoxinA	48 (11)	N/A	19 (10)
OnabotulinumtoxinA	237 (56)	N/A	101 (54)
Other ^c	3 (0)	N/A	0 (0)
Do not know	64 (15)	N/A	34 (18)
Time (in years) since treatment initiation, n (%)			
<2	203 (48)	N/A	68 (36)
2-5	118 (28)	N/A	68 (36)
5-10	61 (14)	N/A	40 (21)
10-15	29 (7)	N/A	8 (4)
>15	16 (4)	N/A	4 (2)
Mean time since treatment initiation, years (95% CI)	3.5 (3.0-3.9)	N/A	3.5 (2.9-4.1)
Concomitant therapy, n (%)			
Alcohol injections	29 (7)	N/A	8 (4)
Botulinum B injections	40 (9)	N/A	24 (13)
Intrathecal baclofen injections	37 (9)	N/A	17 (9)
Phenol injections	45 (11)	N/A	13 (7)
Oral medications ^d	256 (60)	N/A	109 (58)
Physiotherapy at home	151 (35)	N/A	78 (41)
Physiotherapy at hospital/clinic	146 (34)	N/A	56 (30)
Self-rehabilitation (home-based)	79 (19)	N/A	65 (35)
Other	2 (0)	N/A	0 (0)

^aN/A: Not applicable.

^bSelf-reported.

^cFor respondents from Spain only, brand names given were Bocouture, Lantox, and Azzalure.

^dEg, muscle relaxants, baclofen.

Caregiver Profiles

The mean age of caregivers was 38.6 (95% CI 36.9-40.2) years; 55% (104/188) were women and 45% (84/188) were men (Table 1). The mean duration of caregiving was reported as 4.9 (95% CI 4.1-5.7) years, with 12% (22/188) providing care for ≥10 years. Most caregivers (147/188, 78%) provided care either every day

(85/188, 45%) or for ≥4 days a week (62/188, 33%). The patient was a parent of the caregiver in 40% (76/188) of cases, with the remainder being another family member, a friend, a partner, a neighbor, or other. The mean age of caregivers was highest in those providing care for patients with stroke (41.7 years; 95% CI 38.7-44.7) and lowest for traumatic brain injury (35.2 years; 95% CI 30.2-40.2). For MS—the most common cause of

spasticity in this study—caregivers had a mean age of 37.6 (95% CI 34.7-40.6) years.

Caregiver profiles were similar in Europe and the United States, although the latter appeared to spend more time each week in their caregiving role ([Multimedia Appendix 2](#)).

Burden of Spasticity

Employment

Overall, of the 427 patients, 412 patients (96%) were aged <65 years; 69% (284/412) were employed, 1% (6/412) were full-time students, and 30% (122/412) were unemployed ([Table 2](#)). Among patients aged <65 years, 44% (181/412) reported

that their condition had an impact on their professional status, 22% (91/412) reported having to work part-time, and 22% (90/412) were unable to work ([Table 2](#)).

Most caregivers (184/188, 98%) were also aged <65 years. Of these, 29% (53/184) reported that caring for their patient had an impact on their own professional status, including 21% (38/184) who reported having to take a part-time job and 8% (15/184) who did not work in order to take care of their patient ([Table 2](#)).

Compared with the participating European countries, more caregivers in the United States changed their working situation to care for the patient ([Table 3](#)).

Table 2. Burden of spasticity and botulinum neurotoxin type A (BoNT-A) treatment, and the perceived benefits of fewer BoNT-A treatments, for patients and caregivers (N=615).

Variables	Patients (N=427)	Caregivers (N=188)
Employment^a, n (%)	n=412	n=184
Full-time	175 (43)	98 (53)
Part-time, due to condition/caregiving	91 (22)	38 (21)
Do not work due to condition/caregiving	90 (22)	15 (8)
Part-time, not due to condition/caregiving	18 (4)	16 (9)
Do not work, not due to condition/caregiving	32 (8)	8 (4)
Full-time student	6 (1)	7 (4)
Other	0 (0)	2 (1)
Impact of spasticity on time spent at work^a, n (%)	n=412	n=184
Impact	181 (44)	53 (29)
No impact	231 (56)	129 (70)
Other	0 (0)	2 (1)
Time off work due to BoNT-A injection^b, n (%)	n=285	n=156
Never	64 (22)	25 (16)
Sometimes	149 (52)	96 (62)
Often	39 (14)	25 (16)
Always	33 (12)	10 (6)
Number of days taken off work per year due to BoNT-A injection^b, n (%)	n=216	n=121
≤2	51 (24)	21 (17)
3-4	52 (24)	38 (31)
5-9	64 (30)	26 (22)
10-15	26 (12)	18 (15)
>15	23 (11)	18 (15)
Cost (€) per treatment, n (%)	n=330	n=153
0-10	27 (8)	15 (10)
10-30	47 (14)	30 (20)
30-50	27 (8)	14 (9)
50-100	41 (12)	35 (23)
100-300	84 (26)	43 (28)
>300	104 (32)	16 (10)
Out-of-pocket costs^d, n (%)	n=427	n=188
Consultations	153 (36)	61 (32)
Parking	183 (43)	82 (44)
Transportation	235 (55)	114 (61)
Treatments	165 (39)	50 (27)
Reduced salary ^b	99 (23)	63 (34)
Other ^e	2 (0)	0 (0)
None	83 (19)	32 (17)
3 most important perceived benefits of fewer treatments, n (%)	n=427	n=188
Longer periods with improved mobility	196 (46)	N/A ^f

Variables	Patients (N=427)	Caregivers (N=188)
Longer periods not worrying about symptoms	169 (40)	124 (66)
More self-confidence	120 (28)	N/A
Less impact on work activities	115 (27)	92 (49)
More quality time with family and friends	110 (26)	103 (55)
Higher self-esteem	106 (25)	N/A
Less dependence on others	94 (22)	N/A
Less logistical burden	117 (27)	100 (53)
Reliving my fear of injections less frequently	79 (19)	N/A
Less financial burden	1 (0)	2 (1)
Improved quality of life	N/A	1 (1)
I would not experience any benefits	14 (3)	6 (3)

^aOnly including participants who are younger than 65 years of age.

^bAmong those who worked part-time or full-time or answered "other" (patients, n=285; caregivers, n=156); the corresponding percentages are 35% and 40%, respectively.

^cA currency exchange rate of eur 1€=US \$1.18 is applicable.

^dOnly including patients (n=330) and caregivers (n=153) who have to pay something for BoNT-A injections (excluding 14 patients and 3 caregivers who did not answer).

^eFood for patient or driver.

^fN/A: not applicable.

Table 3. Burden of spasticity and botulinum neurotoxin type A (BoNT-A) treatment, and the perceived benefits of fewer BoNT-A treatments, for patients and caregivers in Europe and the United States (N=615).

Variables	Patients & caregivers in Europe (N=315)		Patients & caregivers in the United States (N=300)	
	Patients	Caregivers	Patients	Caregivers
Employment^a, n (%)	n=239	n=65	n=173	n=119
Full-time	92 (38)	38 (58)	83 (48)	60 (50)
Part-time, due to condition/caregiving	48 (20)	10 (15)	43 (25)	28 (24)
Do not work, due to condition/caregiving	60 (25)	3 (5)	30 (17)	12 (10)
Part-time, not due to condition/caregiving	10 (4)	7 (11)	8 (5)	9 (8)
Do not work, not due to condition/caregiving	27 (11)	0 (0)	5 (3)	8 (7)
Full-time student	2 (1)	6 (9)	4 (2)	1 (1)
Other	0 (0)	1 (2)	0 (0)	1 (1)
Impact of spasticity on time spent at work^a, n (%)	n=239	n=65	n=173	n=119
Impact	108 (45)	13 (20)	73 (42)	40 (34)
No impact	131 (55)	51 (78)	100 (58)	78 (66)
Other	0 (0)	1 (2)	0 (0)	1 (1)
Time off work due to BoNT-A injection^b, n (%)	n=150	n=57	n=135	n=99
Never	38 (25)	7 (12)	26 (19)	18 (18)
Sometimes	70 (47)	39 (68)	79 (59)	57 (58)
Often	18 (12)	9 (16)	21 (16)	16 (16)
Always	24 (16)	2 (4)	9 (7)	8 (8)
Number of days taken off work per year due to BoNT-A injection^b, n (%)	n=109	n=47	n=107	n=81
≤2	29 (27)	11 (23)	22 (21)	10 (12)
3-4	25 (23)	9 (19)	27 (25)	29 (36)
5-9	30 (28)	9 (19)	34 (32)	17 (21)
10-15	12 (11)	11 (23)	14 (13)	7 (9)
>15	13 (12)	7 (15)	10 (9)	18 (22)
Cost (€) per treatment, n (%)	n=180	n=54	n=150	n=99
0-10	20 (11)	9 (17)	7 (5)	6 (6)
10-30	30 (17)	10 (19)	17 (11)	20 (20)
30-50	14 (8)	5 (9)	13 (9)	9 (9)
50-100	18 (10)	13 (24)	23 (15)	22 (22)
100-300	38 (21)	11 (20)	46 (31)	32 (32)
>300	60 (33)	6 (11)	44 (29)	10 (10)
Out-of-pocket costs^d, n (%)	n=249	n=66	n=178	n=122
Consultations	64 (26)	17 (26)	89 (50)	44 (36)
Parking	105 (42)	34 (52)	78 (44)	48 (39)
Transportation	130 (52)	41 (62)	105 (59)	73 (60)
Treatments	66 (27)	15 (23)	99 (56)	35 (29)
Reduced salary ^b	34 (14)	21 (32)	65 (37)	42 (34)
Other ^e	0 (0)	0 (0)	2 (1)	0 (0)
None	62 (25)	11 (17)	21 (12)	21 (17)

Variables	Patients & caregivers in Europe (N=315)		Patients & caregivers in the United States (N=300)	
	Patients	Caregivers	Patients	Caregivers
3 most important perceived benefits of fewer treatments, n (%)	n=249	n=66	n=178	n=122
Longer periods with improved mobility	118 (47)	N/A ^f	78 (44)	N/A
Longer periods not worrying about symptoms	94 (38)	41 (62)	75 (42)	83 (68)
More self-confidence	68 (27)	N/A	52 (29)	N/A
Less impact on work activities	60 (24)	30 (45)	55 (31)	62 (51)
More quality time with family and friends	51 (20)	32 (48)	59 (33)	71 (58)
Higher self-esteem	53 (21)	N/A	53 (30)	N/A
Less dependence on others	48 (19)	N/A	46 (26)	N/A
Less logistical burden	75 (30)	31 (47)	42 (24)	69 (57)
Reliving my fear of injections less frequently	50 (20)	N/A	29 (16)	N/A
Less financial burden	0 (0)	0 (0)	1 (1)	2 (2)
Improved quality of life	N/A	0 (0)	N/A	1 (1)
I would not experience any benefits	11 (4)	2 (3)	3 (2)	4 (3)

^aOnly including participants who are younger than 65 years of age.

^bOf 441 participants (patients, n=285; caregivers, n=156) who worked part-time or full-time or answered "other."

^cA currency exchange rate of eur 1€=US \$1.18 is applicable.

^dOnly including patients (n=330) and caregivers (n=153) who have to pay something for BoNT-A injections (excluding 14 patients and 3 caregivers who did not answer).

^eFood for patient and/or driver.

^fN/A: not applicable.

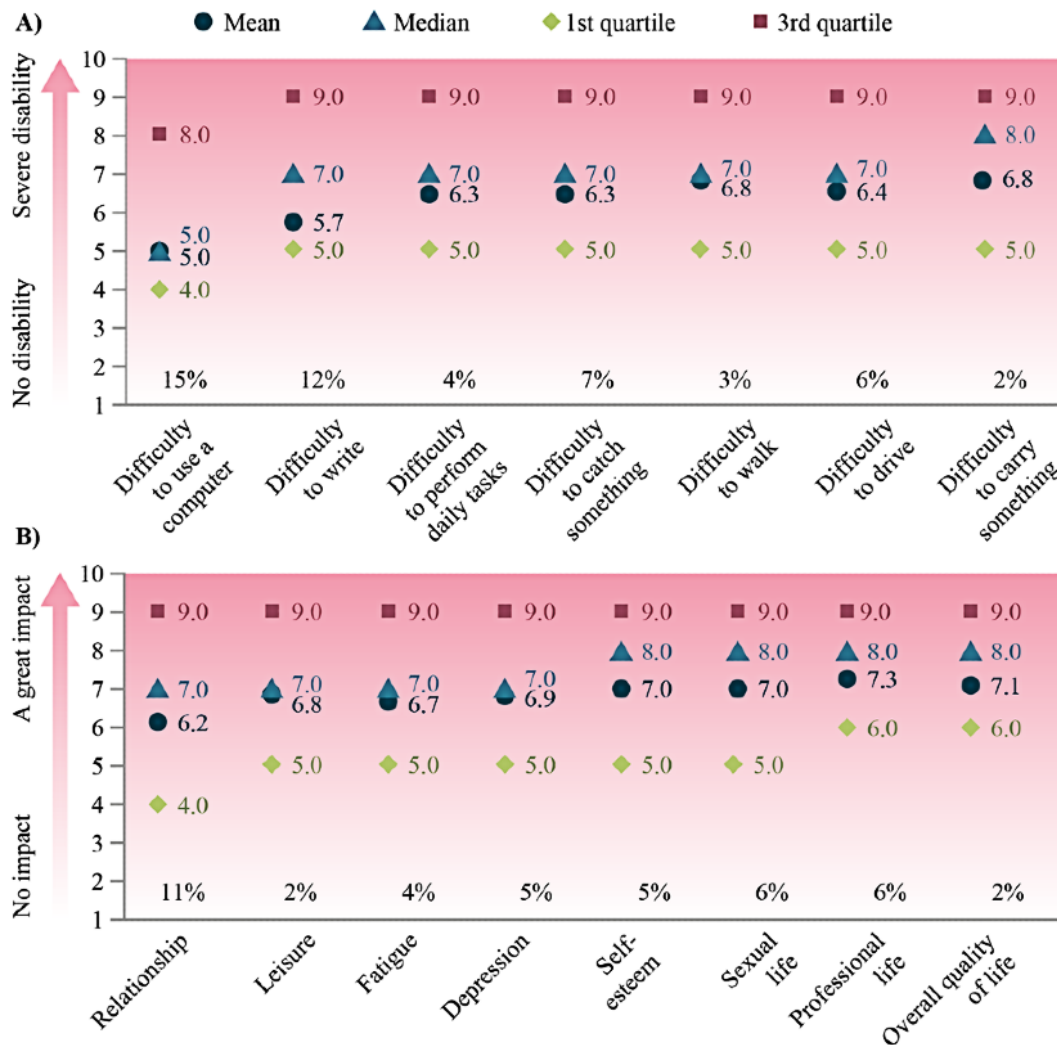
Daily Living and Quality of Life

Scores for the difficulties associated with daily living because of spasticity, as reported by patients, are shown in [Figure 2](#). All median scores were ≥ 5.0 , and the task most affected was carrying things.

At least 85% (364/427) of patients experienced difficulties in ≥ 1 aspect of daily living; aspects most frequently affected were

the ability to carry something (418/427, 98%), walking (414/427, 97%), performing daily tasks (410/427, 96%), and driving (403/427, 94%). Patients with >2 affected limbs experienced the most difficulties with daily living, with 91% (114/125) of patients experiencing 7 difficulties. Patients whose lower limbs only were affected experienced the fewest difficulties, with only 47% (39/83) of patients experiencing 7 difficulties.

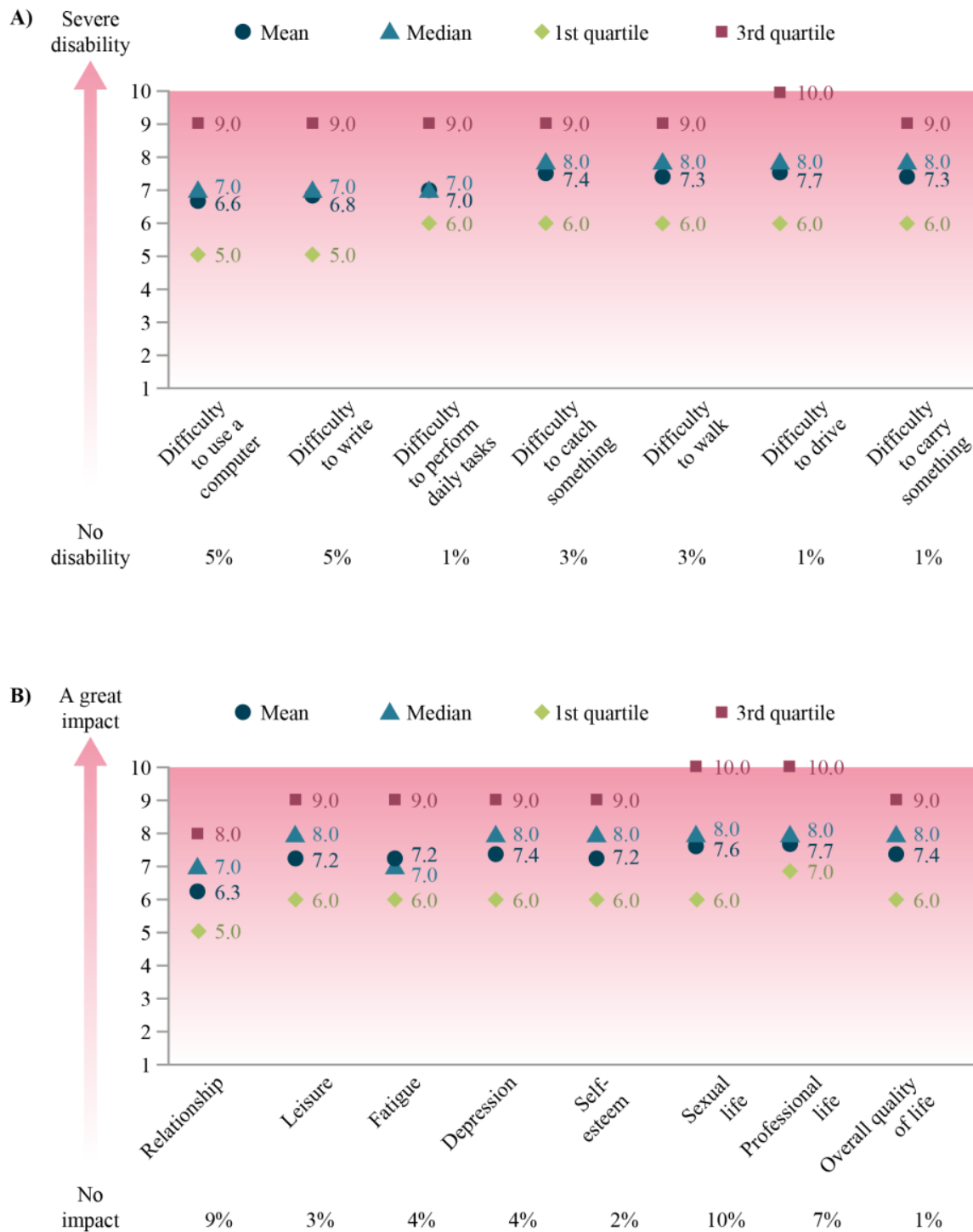
Figure 2. Patient responses on the impact of spasticity on the patients' (A) ability to perform everyday tasks ("For each of the following items, please assess the level of difficulty you experience due to your spasticity," on a scale of 0=no disability to 10=severe disability) and (B) quality of life ("Please assess to what extent spasticity affects your life," on a scale of 0=no impact to 10=a great impact; n=427).



Scores for the impact of spasticity on patients' QoL are shown in Figure 2. All median scores were ≥ 7.0 , with professional life, overall QoL, sexual life, and self-esteem being most affected. At least 89% (381/427) of patients reported that spasticity affected ≥ 1 aspect of their QoL, with leisure (419/427, 98%) and overall QoL (420/427, 98%) being most affected.

Scores for impact on daily living and QoL reported by caregivers (on behalf of patients) are summarized in Figure 3. Caregivers gave slightly higher scores than patients for difficulties with daily living.

Figure 3. Caregiver responses on the impact of spasticity on the patients' (A) daily life ("For each of the following items, please assess the level of difficulty you experience due to your spasticity," on a scale of 0=no disability to 10=severe disability) and (B) quality of life ("Please assess to what extent spasticity affects your life," on a scale of 0=no difficulty to 10=great difficulty; n=188).

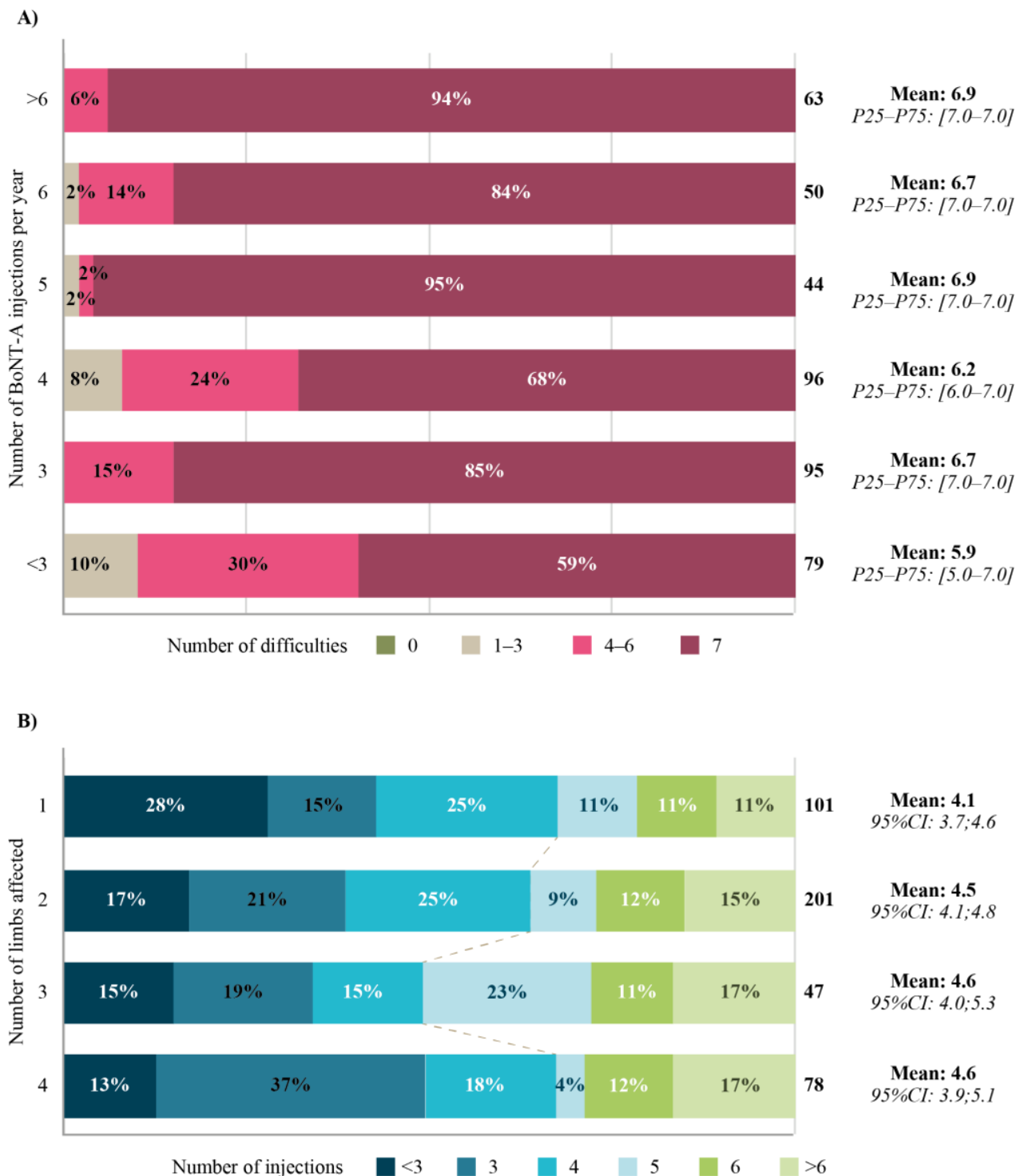


BoNT-A Treatment Behavior

The median (25th percentile-75th percentile) number of patient-reported injections per year was 4.0 (3.0-6.0; 26% of patients received ≥6 injections per year) and was consistent across primary conditions, ranging from 4.0 (3.0-4.0, cerebral palsy) to 5.0 (4.0-8.0, traumatic brain injury), with the exception of brain tumors, which had very few respondents (13/427) and

a median (25th percentile-75th percentile) number of reported injections per year of 3.0 (2.0-3.0). Patients receiving <3 injections per year reported fewer difficulties, and the number of injections per year was not related to the number of affected limbs (Figure 4). The median (25th percentile-75th percentile) number of injections per year was the same between formulations of BoNT-A (4.0, 3.0-6.0, for onaBoNT-A, incoBoNT-A, and aboBoNT-A).

Figure 4. Patient responses to (A) the number of difficulties in activities of daily living, according to the number of botulinum neurotoxin type A (BoNT-A) injections received each year ["On average, how many BoNT-A treatments do you receive per year (numeric response)?" "For each of the following items, please assess the level of difficulty you experience due to your spasticity" (scale, 0=no difficulty and 10=severe difficulty)] and (B) the number of limbs affected according to the number of BoNT-A injections received each year ["In which (how many) limbs do you experience spasticity symptoms (multiple-choice response)?" "On average, how many BoNT-A treatments do you receive per year (numeric response)"] (n=427). P = percentile.



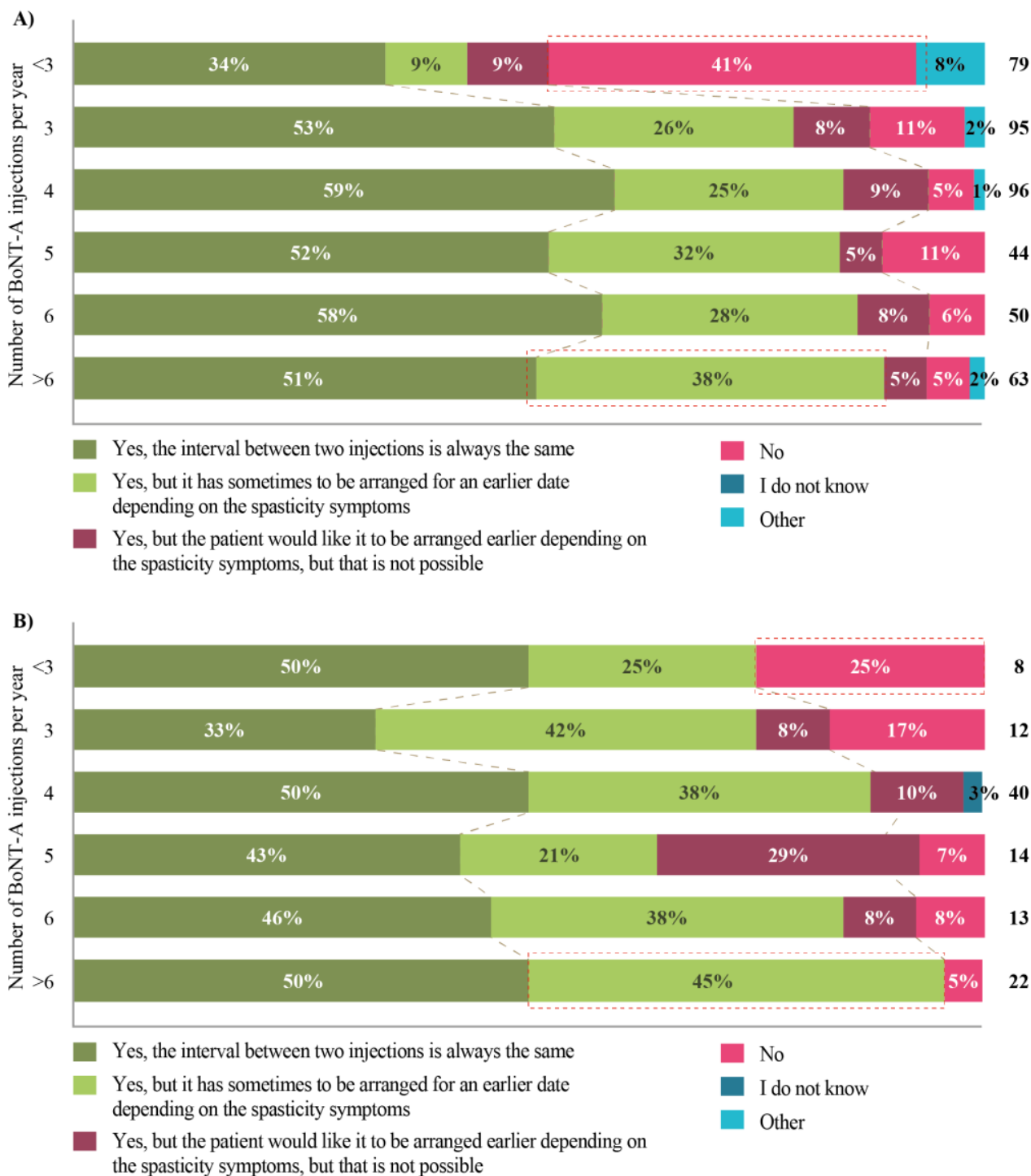
Most patients (371/427, 87%) and caregivers (151/188, 80%) reported that treatment goals were discussed with doctors. The majority of patients (359/427, 84%) also indicated that retreatment was planned immediately after a treatment. This depended on the number of injections per year; retreatment was not planned in 41% (32/79) of patients receiving <3 injections

per year, compared with 11% (10/95) of patients receiving 3 injections per year, 5% (5/96) of patients receiving 4 injections per year, 11% (5/44) of patients receiving 5 injections per year, 6% (3/50) of patients receiving 6 injections per year, and 5% (3/63) of patients receiving >6 injections per year. In approximately one-third of cases (108/359), earlier retreatment

sometimes had to be arranged due to spasticity symptoms, and in 9% (33/359) of cases, patients would have liked to have had earlier retreatment than scheduled, but this was not possible. Among those patients who received >6 injections per year, 38% (24/63) reported that they had to receive earlier retreatment due to spasticity symptoms, whereas for those patients who received

<3 injections per year, only 9% (7/79) reported that they had to receive earlier retreatment due to spasticity symptoms (Figure 5). Caregiver responses for retreatment planning according to the number of BoNT-A treatments per year are presented in Figure 5.

Figure 5. How A) patients (n=427) and B) caregivers (n=109) plan the next treatment date by the number of botulinum neurotoxin A (BoNT-A) treatments received per year ("Do you plan the next treatment date immediately after you get your injections of BoNT-A with your doctor (single-choice response)?" "On average, how many BoNT-A treatments do you receive per year (numeric response)?").



Burden of Receiving BoNT-A Injections

Employment

The majority of employed patients (221/285, 78%) and caregivers (131/156, 84%) had to take time off from employment (defined as any part of a working day) for BoNT-A treatment, and >50% of patients and caregivers took ≥ 5 days off per year (Table 2).

As expected, the number of days patients took off work to receive injections appeared to increase with the number of injections per year. Of the 32 patients who received <3 injections per year, 38% (12/32) required ≥ 3 days off work, compared with 73% (24/33) of patients who received 3 injections per year, 74% (32/43) of patients who received 4 injections per year, 90% (27/30) of patients who received 5 injections per year, 85% (29/34) of patients who received 6 injections per year, and 93% (41/44) of patients who received >6 injections per year.

Issues Associated With BoNT-A Treatment

At least 73% (312/427) of patients reported issues with BoNT-A treatment; cost, availability of timely appointments, fear of injections, and frequency of injections represented the greatest issues [median (25th percentile-75th percentile) scores of 7.0 (4.0-9.0), 7.0 (4.0-8.0), 6.0 (3.0-8.0), and 6.0 (4.0-8.0), respectively]. Among caregivers, at least 84% (157/188) reported issues with BoNT-A treatment, with the cost of injections and logistics representing the greatest burdens to them [median (25th percentile-75th percentile) score 6.0 (5.0-8.0) and 6.0 (4.0-8.0), respectively].

Cost

Overall, 77% of patients (330/427) and 81% of caregivers (153/188) reported that they incurred costs at the time of each

BoNT-A injection. Most patients (303/330, 92%) and caregivers (138/153, 90%) bore a financial cost of >10€ with each BoNT-A treatment, with 57% (188/330) of patients and 39% (59/153) of caregivers paying >100€ with each BoNT-A treatment (Table 2). Over 1 year, 53% (176/330) of patients reported spending >500€ to receive BoNT-A treatment, and the mean cost per year was 1080€ (95% CI 923-1236). (A currency exchange rate of eur 1€=US \$1.18 is applicable.)

Out-of-pocket expenses were experienced by most patients (344/427, 81%) and caregivers (156/188, 83%), with transportation costs and parking fees the most common (Table 2). Among working participants, 35% (99/285) of patients and 40% (63/156) of caregivers reported a reduced salary due to time off work for BoNT-A treatment. More patients in the United States than in participating European countries reported out-of-pocket expenses (Table 3).

Benefits and Concerns About BoNT-A Treatment

Improvements Due to BoNT-A Treatment

Overall satisfaction with life improved with BoNT-A treatment for 92% (393/427) of patients, with a median (25th percentile-75th percentile) improvement score of 7.0 (5.0-9.0). For individual daily task and QoL domains, improvements were reported for 81%-94% (345/427-402/427) of patients, with a median (25th percentile-75th percentile) score for all tasks and domains of 7.0 (5.0-8.0).

Scores for improvements due to BoNT-A reported by patients and caregivers (on behalf of patients) were similar and are presented in Table 4.

Table 4. Scores for patients' and caregivers' responses on improvements in patients' lives with botulinum neurotoxin type A (BoNT-A) treatment; improvement was rated on a scale of 0-10, where 0=no improvement and 10=greatly improved (n=615).

Daily task and QoL ^a domains	Patient (n=427) scores, on a scale of 0-10				Caregiver (n=188) scores, on a scale of 0-10			
	Mean	Median	25 th percentile	75 th percentile	Mean	Median	25 th percentile	75 th percentile
Muscle spasm	6.7	7.0	5.0	8.0	6.6	7.0	6.0	8.0
Pain	6.5	7.0	5.0	8.0	6.4	6.0	5.0	8.0
Ability to perform daily tasks	6.6	7.0	5.0	8.0	6.3	7.0	5.0	8.0
Ability to walk	6.6	7.0	5.0	8.0	6.3	6.0	5.0	8.0
Transfers (moving around, short trips)	6.5	7.0	5.0	8.0	6.3	6.0	5.0	8.0
Fatigue	6.5	7.0	5.0	9.0	6.2	6.0	5.0	8.0
Self-confidence	6.5	7.0	5.0	8.0	6.4	7.0	5.0	8.0
Leisure	6.5	7.0	5.0	8.0	6.3	7.0	5.0	8.0
Personal relationships	6.7	7.0	5.0	9.0	6.5	7.0	5.0	8.0
Ability to socialize	6.6	7.0	5.0	8.0	6.5	7.0	5.0	8.0
Willingness to perform activities	6.7	7.0	5.0	9.0	6.7	7.0	5.0	8.0
Depression	6.5	7.0	5.0	8.0	6.2	6.0	5.0	8.0
Professional life	6.7	7.0	5.0	9.0	6.1	6.0	5.0	8.0
Sexual life	6.5	7.0	5.0	8.0	5.9	6.0	4.0	8.0
Anxiety	6.4	7.0	5.0	8.0	6.1	6.0	5.0	8.0
Overall satisfaction	6.7	7.0	5.0	9.0	6.5	7.0	5.0	8.0

^aQoL: quality of life.

Issues or Concerns About BoNT-A Injections

In response to an open question exploring the main issues or concerns with treatment, patients' most frequently reported issue/concern was side effects (171/427, 40%), namely long-term risks (52/427, 12%), muscular issues (18/427, 4%), urinary incontinence (5/427, 1%), and infections (3/427, 0.7%). Other common concerns included issues with treatment efficacy (95/427, 22%) and administration (75/427, 18%). The former included concerns about lack of effectiveness (51/427, 12%) and long-term loss of efficacy (37/427, 9%), whereas the latter included concerns about pain (27/427, 6%), cost (14/427, 3%), and method of administration (10/427, 2%). In response to the same question, the most frequently reported issue/concern from caregivers was also side effects (93/188, 49%), in particular long-term risks (36/188, 19%). Caregivers also reported concerns regarding the efficacy of treatment (55/188, 29%), namely lack of effectiveness (27/188, 14%), administration of treatment (25/188, 13%), and concerns regarding dosage (6/188, 3%).

No issues or concerns were reported by 15% (63/427) of patients and 10% (18/188) of caregivers.

Perceived Benefits of Requiring Fewer BoNT-A Injections

Assuming a longer duration of effect of BoNT-A, most patients (368/427, 86%) and caregivers (163/188, 87%) believed that they would see fewer BoNT-A treatments per year as a benefit.

In response to an open question posed to 368 patients who believed that fewer BoNT-A injections would be beneficial, the most frequently cited perceived benefits were improved QoL (63/368, 17%), fewer logistical constraints (60/368, 16%), and improved psychological wellbeing (56/368, 15%). At least 79% (338/427) of all patients reported that fewer BoNT-A treatments would improve ≥ 1 aspect of treatment burden, with a median (25th percentile-75th percentile) improvement score of 8.0 each for logistics (5.5-9.0), cost of getting injections (6.0-9.0), and general impact on QoL (6.0-9.0). In response to a prespecified list of potential benefits, the 3 most important benefits of fewer injections reported were longer periods of improved mobility (196/427, 46%), not worrying about symptoms (169/427, 40%), and more self-confidence (120/427, 28%; [Table 2](#)).

In response to an open question to 163 caregivers who believed that fewer BoNT-A injections for their patients would be beneficial to themselves, the most commonly anticipated benefits were fewer logistical constraints (37/163, 23%), lower out-of-pocket expenses (33/163, 20%), and improved psychological wellbeing (30/163, 18%). The 3 most important reported perceived benefits of fewer injections for all caregivers were longer periods not worrying about symptoms (124/188, 66%), more quality time with family and friends (103/188, 55%), and less logistical burden (100/188, 53%; [Table 2](#)).

Only 3% of patients (14/427) and caregivers (6/188) reported not expecting to see any benefits with fewer injections ([Table 2](#)).

For patients, the more BoNT-A injections per year they received, the more benefit they associated with requiring fewer injections: 65% (51/79) who received <3 injections per year expected to feel some or many benefits, compared with 71%-88% receiving ≥3 injections per year [ranging from 71% (67/95) of patients who received 3 injections per year to 88% (44/50) of patients who received 6 injections per year]. Patients who reported experiencing difficulties in receiving BoNT-A treatment were more likely to expect benefits with less frequent injections: depending on the difficulties experienced, 74%-86% (273/427–318/427) answered “yes” to expecting benefits versus 59%-66% (35/427–39/427) who answered “no.”

Expected Reduction in Number of BoNT-A Injections to Achieve Perceived Benefits

The number of BoNT-A injections per year that would be required to achieve perceived benefits was 2 or 3 for most patients and caregivers [62% (228/367) and 71% (73/102), respectively]. Most patients and caregivers felt that 1 or 2 fewer injections per year would beneficially impact their lives (58% [215/367] and 60% [61/102], respectively). Patients receiving the highest number of injections reported the biggest reduction in the number of injections required to perceive benefits (Table 5). Caregiver-reported data (on behalf of their patients) are also presented in Table 5.

Table 5. Expected reduction in the number of botulinum neurotoxin type A (BoNT-A) injections per year to achieve perceived benefits for patients and caregivers, according to the number of injections currently being received ("Assuming the effect of botulinum toxin A injections could last longer, with how many injections per year would you feel the benefit of less frequent injections?").

Patient/caregiver & number of injections per year currently being received	Number of fewer BoNT-A injections per year needed to perceive benefits					
	0	1	2	3	4	>4
Patients (n=367), n (%)						
<4 injections/yr (n=131)	42 (32)	76 (58)	9 (7)	4 (3)	0 (0)	0 (0)
4 injections/yr (n=87)	5 (6)	34 (39)	42 (48)	4 (5)	2 (2)	0 (0)
>4 injections/yr (n=149)	8 (5)	16 (11)	38 (25)	41 (28)	16 (11)	30 (20)
Caregivers (n=102), n (%)						
<4 injections/yr (n=17)	4 (23)	11 (65)	2 (12)	0 (0)	0 (0)	0 (0)
4 injections/yr (n=40)	0 (0)	13 (32)	24 (60)	2 (5)	1 (3)	0 (0)
>4 injections/yr (n=45)	1 (2)	1 (2)	10 (22)	11 (25)	7 (16)	15 (33)

Discussion

Principal Findings

Evidence-based medicine for the treatment of spasticity requires the patient perspective on the burdens of symptoms and receiving treatment, for which there is a knowledge gap. The present survey, which was self-reported by over 600 patients and caregivers in the international Carenity online community, is, to our knowledge, the largest of its kind for those affected by spasticity. The results presented here supplement efficacy and safety data from clinical trials of BoNT-A treatment for spasticity with information on treatment benefits to patients, the effects of symptoms on everyday life, and practical issues associated with treatment. Such insights can inform the development of new patient-reported outcome measures and help guide more effective management of spasticity in clinical practice, thus informing the development of new therapeutics.

The use of online communities is becoming increasingly popular, as they can encourage patients to educate themselves about their condition, motivate patients to participate in clinical research, and are easily accessible; FDA guidance for collecting information from patients who are members of these communities is now available [1,2]. Online communities also offer methodological advantages by providing quick access to a specific patient population, supporting hypothesis generation, improving sociodemographic representativeness, and providing

insights into the feasibility of a study and recruitment for future studies [2]. In this study, only one-fifth of people who had agreed to receive Carenity survey invitations actually participated in our survey, and information regarding the eligibility of those who did not participate is not available, highlighting the challenge of patient and caregiver engagement when using online platforms. However, a high response rate was still achievable as a result of the very large size of the online international community involved.

The presented results confirm that spasticity, irrespective of etiology, has a clear and negative effect on patients' and caregivers' lives. Specifically, patients reported the impact of spasticity on the ability to conduct routine, everyday activities like walking and driving, and on various aspects of QoL. Many patients also reported that spasticity affected their ability to work; among those aged <65 years, 22% changed to part-time working and 22% gave up work completely. In caregivers of working age, the corresponding values were 21% and 8%, respectively. These results are consistent with data from several studies showing that spasticity has a substantial impact on patients' activities of daily living, QoL, and independent living [14,33-35]. They also confirm the results of a study evaluating work restrictions faced by caregivers of patients with spasticity [36].

All the surveyed patients had received treatment with BoNT-A for ≥1 year. Patients and caregivers reported that treatment improved the ability to conduct daily tasks and aspects of QoL

that are affected by spasticity, increasing patients' overall satisfaction with life. Despite its well-established efficacy for spasticity, there was an average gap of 4.8 years between diagnosis and BoNT-A treatment initiation in the population surveyed. However, for conditions such as MS, spasticity may not be present at the initial diagnosis, appearing only later in the disease course. In a previous internet survey among patients with spasticity, almost 50% had to wait 1 year before BoNT was started, and 23% waited >3 years. The authors propose that this may reflect the cost of treatment to health care providers or patients, or a lack of experienced injectors [14]. Regarding costs, reimbursement for BoNT-A by health insurance providers has been decreasing year after year in many countries [37]. In our survey, most patients and caregivers incurred costs at each BoNT-A injection, with >50% of patients reporting an annual expenditure of >500€

Many patients reported practical issues with BoNT-A treatment, including the availability of timely appointments and the frequency of injections. On average, patients received 4.4 injections per year, irrespective of BoNT-A formulation, and, although most planned their visits, some reported scheduling earlier appointments for emergent spasticity symptoms. It is important to note that this was an international study, and treatment intervals were largely dependent on each participating country's health care insurance authorization; therefore, the number of injections per year may be more reflective of this rather than the duration of efficacy or physician guidance. Additionally, these results are dependent on the participant being able to accurately remember how many injections they received per year, and therefore, may be affected by memory bias.

When first asked whether reducing BoNT-A injection frequency (without reducing efficacy) would provide any benefits, 86% (368/427) of patients and 87% (163/188) of caregivers reported that it would, citing factors such as better QoL and fewer logistical constraints. Participants were later asked the same question alongside a prespecified list, from which they had to select the 3 most important benefits of less frequent injections. Only 3% (13/427) of patients and 3% (6/188) of caregivers responded that they would not experience benefits, which suggests that providing a list of potential benefits influenced responses, most likely by enabling participants to envisage benefits they had not been able to foresee previously. Importantly, the 3 most selected benefits (longer periods of improved mobility, not worrying about symptoms, and self-confidence) were related to prolonged symptom relief rather than a reduced number of injections.

Injection Frequency

These data collectively suggest that the option of a longer-acting BoNT-A formulation would be favorably received by patients and their caregivers, to provide sustained relief from spasticity symptoms and to overcome practical issues associated with more frequent treatment, as suggested in another patient survey [38]. A recent clinical review indicates that aboBoNT-A treatment may allow long intervals between injections, suggesting long-term symptom relief [39]. These data appear to be corroborated by real-world evidence [40] and may be

explained by recent preclinical research showing that aboBoNT-A contains more active neurotoxin at licensed doses than other BoNT products [41].

The ability to reduce injection frequency depends on the duration of the effect of the BoNT-A injection. This, in turn, depends on several factors, including dose, muscle mass, and depth of injection [42]. In a model designed to assess the pharmacodynamic effects of aboBoNT-A and onaBoNT-A, the former had a significantly longer duration of action [43]. A Phase 3 trial of aboBoNT-A in patients with lower limb spasticity post-stroke or post-traumatic brain injury permitted retreatment (per the investigator's judgment) at Weeks 12, 16, 20, or 24 [44]. The percentages of patients re-injected at week 16 or later were 20% during the first cycle, 32% during the second cycle, and 15% during the third cycle, indicating that some patients required ≤ 3 aboBoNT-A injections per year. The authors concluded that the long duration of aboBoNT-A may reduce the burden associated with injection frequency [44], which is consistent with the anticipated benefits of less frequent administration in the current study.

Limitations

This study has several limitations. No formal prespecified statistical evaluation took place, and recruitment was conducted via the Carenity website, meaning results may not be representative of the general population of patients with spasticity and their caregivers. The proportion of patients with MS in this survey was higher than would be expected in the general population; in the United States, for example, the incidence of MS is surpassed by both stroke and traumatic brain injury [45]. This survey system self-selected for engaged participants who were familiar with social media and internet platforms. This may explain the relatively large proportion of patients aged under 40 years and patients with MS as a primary etiology for their spasticity, as these patients have been shown to be well-informed and engaged in their condition management, and thus are very active on these platforms [46]. Patients with stroke are typically older (aged >65 years) and may be less likely to engage with online surveys. In addition, it should be considered that caregiver burden may vary with etiology. As discussed, MS was the most common cause of spasticity in this study; however, strokes typically affect older populations and, consequently, patients may have older caregivers, which could potentially cause a higher degree of burden. In this study, there was an age range of 4.1 years between the caregivers of patients with stroke and MS, which does not suggest a greater degree of burden on caregivers of patients with stroke due to older age. However, this small age range may be reflective of the social media aspect of this system, as mentioned previously, rather than the real-world situation. Other limitations were the lack of severity assessment of the patients' spasticity, and that data reflect patients' and caregivers' perceptions of treatment effectiveness rather than accepted clinical endpoints. Additionally, a large proportion of patients received concomitant physiotherapy and oral medications during treatment with BoNT-A; as a result of the nature of this patient survey, it is not possible to deduce how these confounding factors affected patients' and caregivers' perceptions of the efficacy of BoNT-A treatment.

Conclusions

From the patient and caregiver's perspectives elucidated in this study, spasticity represents a great burden on many aspects of their lives, including the ability to work, QoL, and difficulties with daily living. Several challenges were identified with receiving BoNT-A treatment for spasticity, predominantly around scheduling and the associated costs of injections. Despite these challenges, it was established that patients and caregivers perceive that BoNT-A improves patients' lives, with high levels

of overall satisfaction reported. However, patients and caregivers reported that providing efficacy was maintained, BoNT-A injections of reduced frequency would alleviate practical issues associated with treatment and, more importantly, provide prolonged symptom relief. Using an online community enabled more rapid recruitment to the study and data collection regarding patient and caregiver perspectives than would have been possible in a clinical trial or a validation study of patient-reported outcomes.

Acknowledgments

The authors thank all participants involved in this survey. The authors also thank Amy Watkins, PhD, of Watermeadow Medical, an Ashfield company, for providing medical writing support and editorial support, which was sponsored by Ipsen in accordance with Good Publication Practice guidelines.

Conflicts of Interest

ATP received research grants from Ipsen, Merz, Allergan, and Revance, and consultancy fees from Allergan, Ipsen, and Merz. TW received research grants from NIH, Allergan, Alder Pharmaceuticals, Bayer, Boehringer Ingelheim, Acorda Therapeutics Inc, AstraZeneca, Amgen, and Servier; and consultancy fees from Allergan Inc, Boehringer Ingelheim, Bayer, Servier, and Ipsen; steering committee fees from REFLEX, MOBILITY, and Allergan 116; and honoraria from Boehringer Ingelheim, Bayer, Allergan, Pfizer, Merz, Servier, and Ipsen. LB received research grants from Ipsen, Teva, and US World Meds, and consultancy fees from AbbVie, Acadia, Acorda, Adamas, Allergan, Impax, Ipsen, Lundbeck, Neurocrine, Revance, Sunovion, Teva, US WorldMeds, and UCB. OW was an employee of Carenity at the time the research was conducted. CR is an employee of Ipsen. MMF received research grants from Merz, Allergan, and Ipsen.

TW received research grants from NIH, Allergan, Alder Pharmaceuticals, Bayer, Boehringer Ingelheim, Acorda Therapeutics Inc, AstraZeneca, Amgen, and Servier; and consultancy fees from Allergan Inc, Boehringer Ingelheim, Bayer, Servier, and Ipsen; steering committee fees from REFLEX, MOBILITY, and Allergan 116; and honoraria from Boehringer Ingelheim, Bayer, Allergan, Pfizer, Merz, Servier, and Ipsen.

LB received research grants from Ipsen, Teva, and US World Meds, and consultancy fees from AbbVie, Acadia, Acorda, Adamas, Allergan, Impax, Ipsen, Lundbeck, Neurocrine, Revance, Sunovion, Teva, US WorldMeds, and UCB.

OW was an employee of Carenity at the time the research was conducted. CR is an employee of Ipsen. MMF received research grants from Merz, Allergan, and Ipsen.

Multimedia Appendix 1
Questionnaire.

[[DOCX File, 78 KB - publichealth_v6i4e17928_app1.docx](#)]

Multimedia Appendix 2

Participant characteristics in the European Union and the United States.

[[DOCX File, 34 KB - publichealth_v6i4e17928_app2.docx](#)]

References

1. Patient-Focused Drug Development: Collecting Comprehensive and Representative Input: Guidance for Industry, Food and Drug Administration Staff, and Other Stakeholders. 2020 7th July 2020. URL: <https://www.fda.gov/media/139088/download> [accessed 2020-11-13]
2. Ravoire S, Lang M, Perrin E, participants of Giens XXXII Round Table No. 6. Advantages and limitations of online communities of patients for research on health products. *Therapie* 2017 Feb;72(1):135-143. [doi: [10.1016/j.therap.2016.11.058](https://doi.org/10.1016/j.therap.2016.11.058)] [Medline: [28139283](https://pubmed.ncbi.nlm.nih.gov/28139283/)]
3. Carenity website. URL: <https://www.carenity.com/> [accessed 2020-06-25]
4. Pandyan AD, Gregoric M, Barnes MP, Wood D, Van Wijck F, BurrIDGE J, et al. Spasticity: clinical perceptions, neurological realities and meaningful measurement. *Disabil Rehabil* 2005;27(1-2):2-6. [doi: [10.1080/09638280400014576](https://doi.org/10.1080/09638280400014576)] [Medline: [15799140](https://pubmed.ncbi.nlm.nih.gov/15799140/)]
5. John Hopkins Medicine. Spasticity. URL: <https://www.hopkinsmedicine.org/health/conditions-and-diseases/spasticity> [accessed 2020-06-24]
6. Simon O, Yelnik AP. Managing spasticity with drugs. *Eur J Phys Rehabil Med* 2010 Sep;46(3):401-410 [FREE Full text] [Medline: [20927006](https://pubmed.ncbi.nlm.nih.gov/20927006/)]

7. Harb A, Kishner S. Modified Ashworth Scale. In: StatPearls. Treasure Island, Florida: StatPearls Publishing; Jan 2020.
8. Holtz KA, Lipson R, Noonan VK, Kwon BK, Mills PB. Prevalence and effect of problematic spasticity after traumatic spinal cord injury. *Arch Phys Med Rehabil* 2017 Jun;98(6):1132-1138. [doi: [10.1016/j.apmr.2016.09.124](https://doi.org/10.1016/j.apmr.2016.09.124)] [Medline: [27780743](https://pubmed.ncbi.nlm.nih.gov/27780743/)]
9. Pérez-Arredondo A, Cázares-Ramírez E, Carrillo-Mora P, Martínez-Vargas M, Cárdenas-Rodríguez N, Coballase-Urrutia E, et al. Baclofen in the therapeutic of sequela of traumatic brain injury: Spasticity. *Clin Neuropharmacol* 2016;39(6):311-319 [FREE Full text] [doi: [10.1097/WNF.0000000000000179](https://doi.org/10.1097/WNF.0000000000000179)] [Medline: [27563745](https://pubmed.ncbi.nlm.nih.gov/27563745/)]
10. Watkins CL, Leathley MJ, Gregson JM, Moore AP, Smith TL, Sharma AK. Prevalence of spasticity post stroke. *Clin Rehabil* 2002 Aug;16(5):515-522. [doi: [10.1191/0269215502cr512oa](https://doi.org/10.1191/0269215502cr512oa)] [Medline: [12194622](https://pubmed.ncbi.nlm.nih.gov/12194622/)]
11. Zettl UK, Rommer P, Hipp P, Patejdl R. Evidence for the efficacy and effectiveness of THC-CBD oromucosal spray in symptom management of patients with spasticity due to multiple sclerosis. *Ther Adv Neurol Disord* 2016 Jan;9(1):9-30 [FREE Full text] [doi: [10.1177/1756285615612659](https://doi.org/10.1177/1756285615612659)] [Medline: [26788128](https://pubmed.ncbi.nlm.nih.gov/26788128/)]
12. Ghai A, Garg N, Hooda S, Gupta T. Spasticity - Pathogenesis, prevention and treatment strategies. *Saudi J Anaesth* 2013 Oct;7(4):453-460 [FREE Full text] [doi: [10.4103/1658-354X.121087](https://doi.org/10.4103/1658-354X.121087)] [Medline: [24348300](https://pubmed.ncbi.nlm.nih.gov/24348300/)]
13. The Royal College of Physicians of London. Spasticity in adults: management using botulinum toxin. Royal College of Physicians. 2018 Oct 20. URL: <https://www.rcplondon.ac.uk/guidelines-policy/spasticity-adults-management-using-botulinum-toxin> [accessed 2020-11-16]
14. Barnes M, Kocer S, Murie Fernandez M, Balcaitiene J, Fheodoroff K. An international survey of patients living with spasticity. *Disabil Rehabil* 2017 Jul;39(14):1428-1434. [doi: [10.1080/09638288.2016.1198432](https://doi.org/10.1080/09638288.2016.1198432)] [Medline: [27385274](https://pubmed.ncbi.nlm.nih.gov/27385274/)]
15. Clarke NM, Camba GC, Stephens JM, Pulgar S, Bains S, Marchese D, et al. Poster 479 Economic Burden of Pediatric Spasticity in Cerebral Palsy: A Review of the Literature. *PM R* 2016 Sep;8(9S):S316. [doi: [10.1016/j.pmrj.2016.07.398](https://doi.org/10.1016/j.pmrj.2016.07.398)] [Medline: [27673223](https://pubmed.ncbi.nlm.nih.gov/27673223/)]
16. Stevenson VL, Gras A, Bárdos JI, Broughton J. The high cost of spasticity in multiple sclerosis to individuals and society. *Mult Scler* 2015 Oct;21(12):1583-1592. [doi: [10.1177/1352458514566416](https://doi.org/10.1177/1352458514566416)] [Medline: [25623252](https://pubmed.ncbi.nlm.nih.gov/25623252/)]
17. Choi K, Peters J, Tri A, Chapman E, Sasaki A, Ismail F. Goals set by patients using the ICF model before receiving botulinum injections and their relation to spasticity distribution. *Physiotherapy Canada* 2017;69(2):113-119. [doi: [10.3138/ptc.2016-25](https://doi.org/10.3138/ptc.2016-25)] [Medline: [28539691](https://pubmed.ncbi.nlm.nih.gov/28539691/)]
18. Kaku M, Simpson DM. Spotlight on botulinum toxin and its potential in the treatment of stroke-related spasticity. *Drug Des Devel Ther* 2016;10:1085-1099. [doi: [10.2147/DDDT.S80804](https://doi.org/10.2147/DDDT.S80804)] [Medline: [27022247](https://pubmed.ncbi.nlm.nih.gov/27022247/)]
19. Dong Y, Wu T, Hu X, Wang T. Efficacy and safety of botulinum toxin type A for upper limb spasticity after stroke or traumatic brain injury: a systematic review with meta-analysis and trial sequential analysis. *Eur J Phys Rehabil Med* 2017 Apr;53(2):256-267 [FREE Full text] [doi: [10.23736/S1973-9087.16.04329-X](https://doi.org/10.23736/S1973-9087.16.04329-X)] [Medline: [27834471](https://pubmed.ncbi.nlm.nih.gov/27834471/)]
20. Rosales RL, Efendy F, Teleg ES, Delos Santos MM, Rosales MC, Ostrea M, et al. Botulinum toxin as early intervention for spasticity after stroke or non-progressive brain lesion: A meta-analysis. *J Neurol Sci* 2016 Dec 15;371:6-14. [doi: [10.1016/j.jns.2016.10.005](https://doi.org/10.1016/j.jns.2016.10.005)] [Medline: [27871449](https://pubmed.ncbi.nlm.nih.gov/27871449/)]
21. Dressler D, Bhidayasiri R, Bohlega S, Chahidi A, Chung TM, Ebke M, et al. Botulinum toxin therapy for treatment of spasticity in multiple sclerosis: review and recommendations of the IAB-Interdisciplinary Working Group for Movement Disorders task force. *J Neurol* 2017 Jan;264(1):112-120. [doi: [10.1007/s00415-016-8304-z](https://doi.org/10.1007/s00415-016-8304-z)] [Medline: [27787630](https://pubmed.ncbi.nlm.nih.gov/27787630/)]
22. Hoare BJ, Wallen MA, Imms C, Villanueva E, Rawicki HB, Carey L. Botulinum toxin A as an adjunct to treatment in the management of the upper limb in children with spastic cerebral palsy (UPDATE). *Cochrane Database Syst Rev* 2010 Jan 20(1):CD003469 [FREE Full text] [doi: [10.1002/14651858.CD003469.pub4](https://doi.org/10.1002/14651858.CD003469.pub4)] [Medline: [20091546](https://pubmed.ncbi.nlm.nih.gov/20091546/)]
23. Koman LA, Paterson Smith B, Balkrishnan R. Spasticity associated with cerebral palsy in children: guidelines for the use of botulinum A toxin. *Paediatr Drugs* 2003;5(1):11-23. [doi: [10.2165/00128072-200305010-00002](https://doi.org/10.2165/00128072-200305010-00002)] [Medline: [12513103](https://pubmed.ncbi.nlm.nih.gov/12513103/)]
24. Gracies JM, O'Dell M, Vecchio M, Hedera P, Kocer S, Rudzinska-Bar M, International AbobotulinumtoxinA Adult Upper Limb Spasticity Study Group. Effects of repeated abobotulinumtoxinA injections in upper limb spasticity. *Muscle Nerve* 2018 Feb;57(2):245-254 [FREE Full text] [doi: [10.1002/mus.25721](https://doi.org/10.1002/mus.25721)] [Medline: [28590525](https://pubmed.ncbi.nlm.nih.gov/28590525/)]
25. Gracies JM, Esquenazi A, Brashear A, Banach M, Kocer S, Jech R, International AbobotulinumtoxinA Adult Lower Limb Spasticity Study Group. Efficacy and safety of abobotulinumtoxinA in spastic lower limb: Randomized trial and extension. *Neurology* 2017 Nov 28;89(22):2245-2253 [FREE Full text] [doi: [10.1212/WNL.0000000000004687](https://doi.org/10.1212/WNL.0000000000004687)] [Medline: [29093068](https://pubmed.ncbi.nlm.nih.gov/29093068/)]
26. Bethoux F. Spasticity Management After Stroke. *Phys Med Rehabil Clin N Am* 2015 Nov;26(4):625-639. [doi: [10.1016/j.pmr.2015.07.003](https://doi.org/10.1016/j.pmr.2015.07.003)] [Medline: [26522902](https://pubmed.ncbi.nlm.nih.gov/26522902/)]
27. Dashtipour K, Chen JJ, Walker HW, Lee MY. Systematic Literature Review of AbobotulinumtoxinA in Clinical Trials for Lower Limb Spasticity. *Medicine (Baltimore)* 2016 Jan;95(2):e2468 [FREE Full text] [doi: [10.1097/MD.0000000000002468](https://doi.org/10.1097/MD.0000000000002468)] [Medline: [26765447](https://pubmed.ncbi.nlm.nih.gov/26765447/)]
28. Marciniak C, Munin MC, Brashear A, Rubin BS, Patel AT, Slawek J, et al. IncobotulinumtoxinA Treatment in Upper-Limb Poststroke Spasticity in the Open-Label Extension Period of PURE: Efficacy in Passive Function, Caregiver Burden, and Quality of Life. *PM R* 2020 May;12(5):491-499. [doi: [10.1002/pmrj.12265](https://doi.org/10.1002/pmrj.12265)] [Medline: [31647185](https://pubmed.ncbi.nlm.nih.gov/31647185/)]

29. Drexel SC, Klietz M, Kollewe K, Paracka L, Kutschenko A, Kopp B, et al. Caregiver burden and health-related quality of life in idiopathic dystonia patients under botulinum toxin treatment: a cross-sectional study. *J Neural Transm (Vienna)* 2020 Jan;127(1):61-70 [FREE Full text] [doi: [10.1007/s00702-019-02109-6](https://doi.org/10.1007/s00702-019-02109-6)] [Medline: [31802240](https://pubmed.ncbi.nlm.nih.gov/31802240/)]
30. Lambert J, Chekroun M, Gilet H, Acquadro C, Arnould B. Assessing patients' acceptance of their medication to reveal unmet needs: results from a large multi-diseases study using a patient online community. *Health Qual Life Outcomes* 2018 Jul 06;16(1):134 [FREE Full text] [doi: [10.1186/s12955-018-0962-3](https://doi.org/10.1186/s12955-018-0962-3)] [Medline: [29976222](https://pubmed.ncbi.nlm.nih.gov/29976222/)]
31. Yeoman G, Furlong P, Seres M, Binder H, Chung H, Garzya V, et al. Defining patient centricity with patients for patients and caregivers: a collaborative endeavour. *BMJ Innov* 2017 Apr;3(2):76-83. [doi: [10.1136/bmjinnov-2016-000157](https://doi.org/10.1136/bmjinnov-2016-000157)] [Medline: [28890797](https://pubmed.ncbi.nlm.nih.gov/28890797/)]
32. Lamas E, Coquedano C, Bousquet C, Ferrer M, Chekroun M, Zorrilla S. Patients' perception of privacy of personal data, shared in online communities: are we in the presence of a paradox? *Stud Health Technol Inform ?* 2018;251:40. [Medline: [29968647](https://pubmed.ncbi.nlm.nih.gov/29968647/)]
33. Bethoux F, Marrie RA. A Cross-Sectional Study of the Impact of Spasticity on Daily Activities in Multiple Sclerosis. *Patient* 2016 Dec;9(6):537-546. [doi: [10.1007/s40271-016-0173-0](https://doi.org/10.1007/s40271-016-0173-0)] [Medline: [27154536](https://pubmed.ncbi.nlm.nih.gov/27154536/)]
34. Gillard PJ, Sucharew H, Kleindorfer D, Belagaje S, Varon S, Alwell K, et al. The negative impact of spasticity on the health-related quality of life of stroke survivors: a longitudinal cohort study. *Health Qual Life Outcomes* 2015 Sep 29;13:159 [FREE Full text] [doi: [10.1186/s12955-015-0340-3](https://doi.org/10.1186/s12955-015-0340-3)] [Medline: [26415945](https://pubmed.ncbi.nlm.nih.gov/26415945/)]
35. Zorowitz RD, Gillard PJ, Brainin M. Poststroke spasticity: sequelae and burden on stroke survivors and caregivers. *Neurology* 2013 Jan 15;80(3 Suppl 2):S45-S52. [doi: [10.1212/WNL.0b013e3182764c86](https://doi.org/10.1212/WNL.0b013e3182764c86)] [Medline: [23319485](https://pubmed.ncbi.nlm.nih.gov/23319485/)]
36. Ganapathy V, Graham GD, DiBonaventura MD, Gillard PJ, Goren A, Zorowitz RD. Caregiver burden, productivity loss, and indirect costs associated with caring for patients with poststroke spasticity. *Clin Interv Aging* 2015;10:1793-1802 [FREE Full text] [doi: [10.2147/CIA.S91123](https://doi.org/10.2147/CIA.S91123)] [Medline: [26609225](https://pubmed.ncbi.nlm.nih.gov/26609225/)]
37. Schnitzler A, Ruet A, Baron S, Buzzi JC, Genet F. Botulinum toxin A for treating spasticity in adults: costly for French hospitals? *Ann Phys Rehabil Med* 2015 Oct;58(5):265-268 [FREE Full text] [doi: [10.1016/j.rehab.2015.06.004](https://doi.org/10.1016/j.rehab.2015.06.004)] [Medline: [26234276](https://pubmed.ncbi.nlm.nih.gov/26234276/)]
38. Jacinto J, Varriale P, Pain E, Lysandropoulos A, Esquenazi A. Patient Perspectives on the Therapeutic Profile of Botulinum Neurotoxin Type A in Spasticity. *Front Neurol* 2020;11:388 [FREE Full text] [doi: [10.3389/fneur.2020.00388](https://doi.org/10.3389/fneur.2020.00388)] [Medline: [32477251](https://pubmed.ncbi.nlm.nih.gov/32477251/)]
39. Esquenazi A, Delgado MR, Hauser RA, Picaut P, Foster K, Lysandropoulos A, et al. Duration of Symptom Relief Between Injections for AbobotulinumtoxinA (Dysport) in Spastic Paresis and Cervical Dystonia: Comparison of Evidence From Clinical Studies. *Front Neurol* 2020;11:576117 [FREE Full text] [doi: [10.3389/fneur.2020.576117](https://doi.org/10.3389/fneur.2020.576117)] [Medline: [33101184](https://pubmed.ncbi.nlm.nih.gov/33101184/)]
40. Turner-Stokes L, Ashford S, Fheodoroff K, Brashear A, Maisonobe P, Lysandropoulos A. Time to retreatment with botulinum toxin A in upper limb spasticity management: Upper limb international spasticity (ULIS)-III study interim analysis. *Toxicon* 2018;156:S110-S1S1. [doi: [10.1016/j.toxicon.2018.11.266](https://doi.org/10.1016/j.toxicon.2018.11.266)]
41. Field M, Splevins A, Picaut P, van der Schans M, Langenberg J, Noort D, et al. AbobotulinumtoxinA (Dysport), OnabotulinumtoxinA (Botox), and IncobotulinumtoxinA (Xeomin) Neurotoxin Content and Potential Implications for Duration of Response in Patients. *Toxins (Basel)* 2018 Dec 13;10(12):535 [FREE Full text] [doi: [10.3390/toxins10120535](https://doi.org/10.3390/toxins10120535)] [Medline: [30551641](https://pubmed.ncbi.nlm.nih.gov/30551641/)]
42. Samizadeh S, De Bouille K. Botulinum neurotoxin formulations: overcoming the confusion. *Clin Cosmet Investig Dermatol* 2018;11:273-287 [FREE Full text] [doi: [10.2147/CCID.S156851](https://doi.org/10.2147/CCID.S156851)] [Medline: [29910630](https://pubmed.ncbi.nlm.nih.gov/29910630/)]
43. Nestor MS, Ablon GR. Duration of action of abobotulinumtoxinA and onabotulinumtoxinA: a randomized, double-blind study using a contralateral frontalis model. *J Clin Aesthet Dermatol* 2011 Sep;4(9):43-49 [FREE Full text] [Medline: [21938269](https://pubmed.ncbi.nlm.nih.gov/21938269/)]
44. Isner-Horobeti ME, Gracies JM, Brashear A, Esquenazi A, O'Dell M, Deltombe T. Duration of effect of abobotulinumtoxinA (Dysport®) in adult patients with lower limb spasticity post-stroke or traumatic brain injury. *Ann Phys Rehabil Med* 2017;60 (suppl.):e26-e27.
45. Ma VY, Chan L, Carruthers KJ. Incidence, prevalence, costs, and impact on disability of common conditions requiring rehabilitation in the United States: stroke, spinal cord injury, traumatic brain injury, multiple sclerosis, osteoarthritis, rheumatoid arthritis, limb loss, and back pain. *Arch Phys Med Rehabil* 2014 May;95(5):986-995.e1. [doi: [10.1016/j.apmr.2013.10.032](https://doi.org/10.1016/j.apmr.2013.10.032)] [Medline: [24462839](https://pubmed.ncbi.nlm.nih.gov/24462839/)]
46. Kantor D, Bright JR, Burtchell J. Perspectives from the Patient and the Healthcare Professional in Multiple Sclerosis: Social Media and Participatory Medicine. *Neurol Ther* 2018 Jun;7(1):37-49 [FREE Full text] [doi: [10.1007/s40120-017-0088-2](https://doi.org/10.1007/s40120-017-0088-2)] [Medline: [29222700](https://pubmed.ncbi.nlm.nih.gov/29222700/)]

Abbreviations

- BoNT-A:** botulinum neurotoxin type A
- CI:** confidence interval
- CNS:** central nervous system

FDA: US Food and Drug Administration

MS: multiple sclerosis

QoL: quality of life

Edited by G Eysenbach; submitted 31.01.20; peer-reviewed by D López López, IV George, K Ferrini; comments to author 12.06.20; revised version received 05.08.20; accepted 20.10.20; published 07.12.20.

Please cite as:

Patel AT, Wein T, Bahroo LB, Wilczynski O, Rios CD, Murie-Fernández M

Perspective of an International Online Patient and Caregiver Community on the Burden of Spasticity and Impact of Botulinum Neurotoxin Therapy: Survey Study

JMIR Public Health Surveill 2020;6(4):e17928

URL: <http://publichealth.jmir.org/2020/4/e17928/>

doi: [10.2196/17928](https://doi.org/10.2196/17928)

PMID: [33284124](https://pubmed.ncbi.nlm.nih.gov/33284124/)

©Atul T Patel, Theodore Wein, Laxman B Bahroo, Ophélie Wilczynski, Carl D Rios, Manuel Murie-Fernández. Originally published in JMIR Public Health and Surveillance (<http://publichealth.jmir.org>), 07.12.2020. This is an open-access article distributed under the terms of the Creative Commons Attribution License (<https://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in JMIR Public Health and Surveillance, is properly cited. The complete bibliographic information, a link to the original publication on <http://publichealth.jmir.org>, as well as this copyright and license information must be included.

Publisher:
JMIR Publications
130 Queens Quay East.
Toronto, ON, M5A 3Y5
Phone: (+1) 416-583-2040
Email: support@jmir.org

<https://www.jmirpublications.com/>